Queensland Advocacy Incorporated

Our mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Systems and Legal Advocacy for vulnerable people with Disability

13 July 2017

Dear Commissioners

Please accept our submission and comments on the NDIS Costs position paper.

QAI thanks the Productivity Commission for the opportunity to make a submission on the issues paper.

Yours sincerely

Michelle O'Flynn

Submit online at http://www.pc.gov.au/inquiries/current/ndis-costs/make-submission#lodge

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About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (QAI) is a community-based association that provides systemic, individual and legal advocacy for people with disability. Our mission is to promote, protect and defend the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

QAI has an exemplary track record of effective systems advocacy, with thirty years' experience advocating for systems change, through campaigns directed to attitudinal, law and policy reform and by supporting the development of a range of advocacy initiatives in this state. We have provided, for almost a decade, individual advocacy through our Human Rights Legal Service, the Mental Health Legal Service and the Justice Support Program. These services have provided us with a wealth of knowledge and understanding about the challenges, issues, needs and concerns of individuals who are the focus of this inquiry.

QAI deems that all humans are equally important, unique and of intrinsic value and that all people should be seen and valued, first and foremost, as a whole person. Further, QAI believes that all communities should embrace difference and diversity, rather than aspiring to an ideal of uniformity of appearance and behaviour. Central to this, and consistent with our core values and beliefs, QAI will not perpetuate use of language that stereotypes or makes projections based on a particular feature or attribute of a person or detracts from the worth and status of a person with disability. We consider that the use of appropriate language and discourse is fundamental to protecting the rights and dignity, and elevating the status, of people with disability.

Queensland Advocacy Incorporated Recommendations

- The inertia of older, inferior, bureaucratic and top-down disability support is dragging the 2011 vision under. An NDIS that is a bigger version of the old systems will cost more than a new one focussed on empowerment, and time is running out.

- Invest in and support self-direction and management, where a portable package of funds gives persons with disabilities control over how they purchase their disability supports.

- Incentivise self-direction by providing substantial benefits to people who choose it.

- States are withdrawing from services that *need* to be block-funded, such as community mental health services; prison and forensic transition supports; information and referral services; the training of guide dogs; 'Community Care' health services such as drop in wound and continence care, podiatry and footwear; and assistance services that do small building modifications such ramp installation, gardening mowing and maintenance.

- The NDIA should devote a portion of its resources to testing the reliability and validity of supports. Where possible this should be done at arms' length, to avoid accusations of bias.

- Queensland Advocacy Incorporated is funded to assist participants and would-be participants with internal and external reviews. In participant rules and operational guidelines we know of anomalies that, if categorized more plainly, would prevent unnecessary and costly review processes.

- If the NDIS is not to backslide into a larger version of old disability services it must allow plan self-managers to innovate, experiment and take risks. Innovation will come from small and growing numbers of people with disability and their families who are choosing self-management.

- Many potential participants need supports to get their plans right, and the NDIA can do more to encourage plan development services.

- Where people are highly vulnerable or live with Restrictive Practices it is essential that their supports are consistent, reliable and that the workers know and understand the person very well, and work within a 'right relationship' arrangement. Service providers allowed to employ 457 visa workers will undermine good relationships and inevitably there will be increases in applications for more types and frequents uses of Restrictive Practices, and more injury claims either by 457 staff or by the participants themselves.

1. Introduction

The NDIS is not just about new funding: it will reduce the funding required for a range of existing federal and state government programs. In 2011 the Australian government actuary identified offsets of $11 billion, so the NDIS net cost is close to $11 billion. At maturity the NDIS will deliver GDP benefits of up to $23 billion. The new system, too, will be more equitable and sustainable than the pre-NDIS grants-based, supplier driven, highly regulated, inequitable and inconsistent across state borders model, where funding changes were applied inconsistently, creating volatility and uncertainty.[1]

According to recent modelling, the old system would have exceeded the NDIS cost by 2025. In terms of creating new jobs and assisting people with disabilities, and carers, into the workforce the net benefit of the scheme could be between $18 to $23 billion, and support 25,000 - 40,000 FTE jobs for people with disabilities.

The scheme could do with a marketing campaign to counteract the distorted, negative picture in the media, particularly in small-government promoting publications such as *The Australian*. The ultimate test of longevity of the scheme is, arguably, the Australian taxpayer's willingness to pay for it.

Some media have already taken sides in that battle for hearts and wallets, and the NDIA and the Commonwealth must do more to reshape the public perception of the scheme as one, potentially, for all of us. Disability is a human condition that affects all people including family, friends or neighbours, directly or indirectly at potentially any time.

one car or bicycle accident away for any of us, and if that happens, we will want to have some control over the services we arrange for ourselves.

2. Scheme Eligibility

2.1 Early Intervention Screening

Queensland Advocacy Incorporated is not expert in screening and eligibility. We observe, however, that early intervention supports designed to prevent or mitigate deficits should be carefully monitored.

Parents are aware that their young children have a disability that is as yet not named but may need assistance of sorts. The NDIS must support the needs of the child to enable the families to live typical lives without overburdening them with an ongoing search for diagnosis, assessments, therapies, treatments that diverge from ordinary family life. The NDIS is meant

[1] Citi Research < https://ir.citi.com/LIRJf4E9V0RDSWvifyrPygQvuVHDT%2Fu9ijhbb2ykjY6BxZDJKi%2BaXMbmCLndAi2ixSa8kzz7ugI%3D>

to provide the supports as, how, and where needed but also intervention to prevent further disadvantage if possible. It would be contrary to the intent and purpose of the Scheme if the Early Intervention access prompts families to over-reach in fear of losing supports that might be required as they seek eligibility for their children.

2.2 Interface Principles

The Interface Principles cannot cover every contingency. We accept that some forms of support will fall into the grey 'second column' found in tables in the Operational Guidelines that sets out areas of support that may be either the responsibility of the NDIA or mainstream services.

Queensland Advocacy Incorporated is funded to assist participants and would-be participants with internal and external reviews. We are aware of anomalies that, if categorized more plainly, would prevent unnecessary and costly review processes.

In Queensland, for example, state-funded mainstream services such as Community Care (formerly Home and Community Care, or 'HACC') have taken the view that any person with an NDIS plan is no longer entitled to their (Community Care) support. In practice, this policy has left some participants in limbo when both the NDIS and Community Care disavowed their responsibility to provide health-related clinical supports to a woman requiring nursing services including a catheter change at home, the former because such supports are not reasonable and necessary, and the latter because the participant now has an NDIS plan.

Discrimination is being experienced by people who live with restrictive practices. They are denied the right to self-direct and self-employ their staff, despite the fact that they are doing reporting and data collection as traditional service providers. Instead, the NDIS should be allowed to purchase their own supports. That will be more cost effective, efficient, person-centred and by empowering people will establish a foundation for the reduction and elimination of Restrictive Practices. The NDIS must be fair and equitable and not deny any participants the same access, freedoms and opportunities as any other.

2.3 Psycho-social Disability

Much will depend on the findings of the Joint Standing Committee on the NDIS's inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a

mental health condition.[2] Queensland Advocacy Incorporated is not aware that the NDIA and local Corrective Services, Forensic Services and the courts are talking to one another and collectively developing pathways out of the criminal justice system. Success in assisting people to move out of the criminal justice cycle depends on a coordinated approach.

Under the former dispensation, a person in custody will not get a support package until released and will not be released until they get a support package - a catch 22 that the NDIA must address. The COAG interface principles are an important way to explain who has which responsibility but they also promote cooperation and working together. It is critically important that the NDIS is proactive in talking to corrective services, the chief magistrate and the courts about how they can work together to provide pathways out of criminal justice and forensic systems.

In Queensland we see 'responsibility flight' as the state seeks to abdicate from disability and mental health leadership. The NDIS is an opportunity for the states to cut and run, but collaboration and coordination are key. Deinstitutionalization from forensic detention, prisons (where people with disabilities are incarcerated at a rate at least 4x that of the general population) authorized mental health facilities and group homes can only happen if the provision of disability supports (via the NDIS) is coordinated with, for example, decision-making, housing, justice, mental health and income support.

3. Supports and Plans

Increased package costs may be due to the shrinking of other disability services, and because there is a general presumption that all services will now be purchased through the NDIS. People with disability and their families have shared information and experiences and therefore are more enlightened to the possibilities offered by the Scheme. Many would-be participants have realised that 'my first plan' or their previous support experiences were inadequate, and this raised awareness and empowerment may impact package costs. 'Planning by phone' and hurried implementation means that many plans are inadequate, and packages need to be increased on review.

3.1 Slower Planning

According to NDIA promotional material, Local Area Coordinators will meet with participants, families and carers to talk about current support networks, understand what people want to achieve and develop a plan to help them get there; help people to find and access the best support services to meet their needs; assist participants in managing any issues they face getting services and support; and link participants to information and support in the community so they actively are included.

[2] http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth

This sounds great, but too many participants have negotiated their plans over the telephone, and planning at arm's length is only likely to become more common as pressure builds to reach participant targets. Potential participants need more supports to get their plans right, and this means the NDIA must do more to encourage plan development services. The NDIA can do this by funding small independent organisations to work with participants in 'pre-planning' thinking. Participants could be supported to develop their own plan proposals as part of their application to enter the scheme.

3.2 Invest in Self-direction

The United Kingdom introduced direct payments in 1996, making it possible for people with disability to control their money. In the UK about 16% of people take a direct payment and spend it in pursuit of a defined set of outcomes.

Table 1.3.1. Trends in proportion of participants using each, or a combination, of plan management options[1]

State	Agency Managed	Combination	Self-Managed
NSW	51%	47%	1%
SA	70%	19%	12%
TAS	50%	46%	4%
VIC	72%	28%	0%
ACT	50%	37%	13%
NT	92%	8%	0%
WA	67%	26%	7%
Total	63%	32%	5%

Source: Australian department of Human Services. *NDIA 7th Quarterly Report to COAG Disability Reform Council* <https://www.ndis.gov.au/part3-participant-3.html#1>

Table 1.3.1 shows the distribution of plan management options being used by active[2] participants. 5% of plans are solely self-managed, and 32% of plans use a combination of agency management and self-management, up from 4% and 29% in the last quarter respectively.

Note: the management of the plan in this instance refers to the financial management of the plan. Participants can self-direct their supports whilst the agency manages the financial side of the plan.

Self-direction is the trend in disability services throughout much of Western Europe and North America, but as shown in the table above, Australia's NDIS is lagging behind.

Evidence suggests that when individuals have greater choice and control over their services, they are more likely to have better outcomes and to make more efficient and effective use of money: [3] for example, a Brisbane-based consulting service in self-management advises us that a self-managing client's $200 000 annual package would be a $350 000 package through a disability service provider.

Passive consumption is –

- Contrary to the original scheme goals
- Disempowering for persons with disabilities
- No cheaper, and in the long term, more expensive.

The surest way to increase costs is to encourage passive service consumption. It is more cost effective and efficient for individuals to control how their money is spent. We need further research to confirm this.[4]

Self-direction and individual funding is win/win for people with disabilities and for the scheme's budget, but the NDIA must actively invest in self-direction and empowerment. The more people feel in 'control' of their supports the more they invest in positive outcomes, the better their long-term prospects, the better their sense of well-being, and the lower their spending on support. Incentivise self-direction by providing substantial benefits to people who choose it.

A majority of NDIS participants have their individualised funding 'agency managed'. They can choose the provider of their supports from a list of NDIS registered service providers, and these providers claim their payment directly from the NDIA.

The agency managed approach is rigid, although some registered service providers offer flexibility by brokering limited funds for community activities. Generally, the agency managed approach replicates the way disability services traditionally have been delivered.

The other options are 'self-managed', which is direct payment of funding to the participant, and 'plan managed', where a financial intermediary handles the funding and administration. These options allow much greater flexibility as participants can choose supports and services from registered and non-registered providers. This might be as simple as choosing a regular cleaner sub-contractor to assist in domestic chores instead of having to choose a disability specific registered provider, as you must with agency managed, or using sites like Gumtree to hire support staff who work exclusively for the participant or their family.

If the NDIS is not to slide back into a much larger version of pre-NDIS disability services it will need to allow plan self-managers to innovate, experiment and take risks. Innovation will

[3] Eleanor Malbon, Gemma Carey, Helen Dickinson. 2017. Accountability in Public Service Quasi-markets: The Case of the Australian National Disability Insurance Scheme in The Australian Journal of Public Administration.

[4] Many self-directing consumers spend less than their allocated allowance, according to research by V Alakeson 2007 'Direct dollars', *Mental Health Today*, 16–18.; A Barczyk & J Lincove. 2010. 'Cash and counseling: a model for self-directed care programs to empower individuals with serious mental illnesses' in *Social Work in Mental Health*, 8 (3), 209–224.; J Cook *et al.* 2008. 'Economic grand rounds. A self-directed care model for mental health recovery', *Psychiatric Services*, 59 (6), 600–602.

come from the small and hopefully growing number of people with disability and their families who are choosing self-management and plan-management of NDIS funds.

Choice and control are at the heart of self-direction, instead of the passive receipt of underfunded block services that provide little flexibility and a one-size-fits-all approach geared to the needs of the system rather than those of people with disability. Invest in self-direction and individual funding, where a particular person's portable package of funds facilitates control over how they purchase their disability support needs.

Encourage self-direction by ensuring that Local Area Coordinators (LAC's) prefer Plan Management Services with built-in obsolescence: services that will support participants to build their financial and staff management skills towards independence. Finally, investigate the potential for persons with disabilities who currently live with Restrictive Practices to self-direct their supports and services so that they may gain control and empowerment in their lives and inevitably move towards reduction and it elimination of the use of these practices wherever possible.

3.3 De-regulate Plan Spending[5] and Encourage a 'Bottom-up' System

The best services are innovative, cost-effective and responsive to consumers, but the danger is that excessive regulation of spending will encourage providers to -

- offer standardised 'take-it-or-leave-it' service delivery to disempowered consumers, who take whatever services are on offer
- offer standardized service contracts that are less 'person-centred' and more calculated to get the best for the service
- focus on short-term outcomes rather than overcoming long-term barriers
- remain heavily regulated and controlled by government, and
- focus not on service goals rather than outcomes for participants, as originally promised.

Tabloid and conservative media are keen to claim that NDIS money is being frittered away. The *Herald Sun* has claimed that participants have purchased 'animal whisperers, soul

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'Agency managed' = (the majority of) participants choose the provider of their supports from a list of registered providers, and these providers claim their payment directly from the NDIA. Replicates traditional disability service delivery.
'Self managed' = direct payment of funding to the participant.
'Plan managed = a financial intermediary handles funding and admin.
'Self' and 'Plan' managed arrangements allow more flexibility. Participants can choose supports and services from registered *and* non-registered providers. More flexible. Manage tax and payroll.

counsellors and spiritual coaches'[6] rather than used for the strict care requirements of participants' impairments. The result has been a demand for increased control over spending.

Media reporting[7] about alleged NDIS funding for alternative medicines, energy healing, yoga, chiropractic therapy and other supports that have little or no evidence-base is that government can more readily impose income management systems for participants in order to ensure that 'taxpayer's money' is spent only on things which pass certain morality checks. Contrary to sensational reporting, however, people can spend money only on things which would count as 'disability relevant'; a constrained list that is focussed around medical interventions and medical care.

If the NDIS acts like an insurance product by being preventative, keeping people well and reducing demand for more intensive care, then it needs to provide what people think is important to them. People with chronic and complex disabilities all experience life in different ways and have different priorities just like the rest of the population. A problem with traditional services is that they tend to put people into similar sorts of boxes in ways we know are often ineffective and inefficient.

Allowing participants to choose alternative medicines, yoga, chiropractic therapy and other supports that may have little or no evidence-base is not just about giving people what they want. It is a way of testing the market and fostering innovation. The NDIS will need to allow people to spend money on a wider range of goods and services in order to promote service innovation and different outcomes. NDIS participant spending on traditional services inevitably will produce more of the same sorts of outcomes.

3.4 Invest in NDIS Feedback Mechanisms such as an Intervention Evidence-base

One of the objects of the *National Disability Insurance Scheme Act 2013* (Cth) is to promote the provision of high quality and innovative supports, having regard to current good practice. A support may be effective and beneficial where its aim is to enable the person to engage in social and economic activities. There may be no valid data, however, that tells us whether some supports are effective or beneficial.

This is true of some early intervention supports, for example, because there has been insufficient time rigorously to determine their value. Such Supports rightly may attract media scepticism, undermining the whole Scheme, and given the high demand on limited resources they will not represent value for money.

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[6] Natasha Bita. 2017. 'National Disability Insurance Scheme: Funding going to animal whisperers, soul counsellors and spiritual coaches' in *The Daily Telegraph*. 2 June, http://www.dailytelegraph.com.au/news/nsw/ndis-billions-unconventional-treatment-providers-register-for-public-funding/news-story/16e1047275774eba47da8070e2886c13.

[7] Rick Morton, 2016. 'NDIS to Cover Alternative Therapy' in *The* Australian 22 April; Natasha Bita. 2017. 'National Disability Insurance Scheme: Funding going to animal whisperers, soul counsellors and spiritual coaches' in *The Daily Telegraph*, 2 June < http://www.dailytelegraph.com.au/news/nsw/ndis-billions-unconventional-treatment-providers-register-for-public-funding/news-story/16e1047275774eba47da8070e2886c13>.

The NDIA should devote a portion of its resources to testing the reliability and validity of supports. Where possible this should be done at arms' length, to avoid accusations of bias.

3.5 Promote Choice in a Free-market of Service Providers

Participants' freedom of choice is critical to scheme longevity, reducing monopolizing tendencies which disadvantage service consumers by reducing competition and increasing suppliers' bargaining power. Service Providers can dictate the terms of contracts, leaving persons with disabilities in a position where they can 'take-it-or-leave-it'.

The decision to allow service providers to do support coordination, even at arm's length, creates a conflict of interest. There is little to prevent a support coordinator from exhibiting bias towards their organization's service provision.

4. Work and Workforce

4.1 Accessible Work Equals Less Need for Support

One of the NDIS' principal benefits is in providing the supports for participants to enter or to stay in the workforce. Workforce participation, however, is not only a demand-side problem. Good support will not get every person with intellectual impairment a job. The Third Sector leads the way here, but public and private employers must too commit to providing accessible workplaces.

Labour force participation has *decreased* relative to people without disabilities over the last two decades. In 1993, the employment participation rate for people with disabilities was 55%, and broadly similar in 2009 at 54%. Over the same period, the participation rate for working-age people with no disability increased from 77% in 1993 to 83% in 2009. [8]

[8] Australian Bureau of Statistics,('ABS') Australian Social Trends, March Quarter 2012: Disability and Work. http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features40March+Quarter+2012

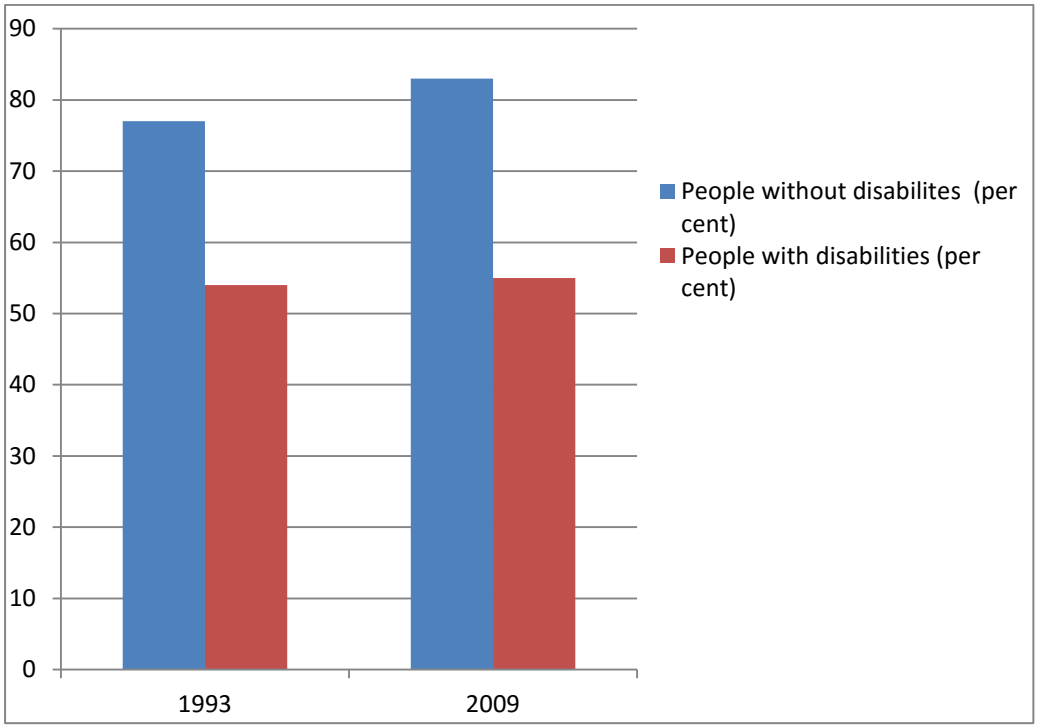

Fig1. Employment Participation Trends 2003-2009: People with and without disabilities

The NDIS was never intended as a panacea, and there can be no reasonable expectation that labour force participation will improve without resources directed towards access. Queensland Advocacy Incorporated notes that people with disability will still need advocates who can assist them with those concerns.

4.2 The 457 Solution

The use of temporary visas to ensure sufficient supply of lower skill personal carers may be a short-sighted and ill-suited response to real problems of long-term under-investment in the sector's greatest asset: its frontline workforce. The '457 solution' is poorly aligned with the NDIS' vision of promoting the capacity of consumers to choose their own support staff, and in some cases to employ them directly, because 457 visa holders can only be employed by organisations, not by individuals.

A temporary workforce is less than ideal for people with disabilities and their families. Support is labour intensive, and the personal element of the work means the security and consistency of sustained relationships is the key to quality. These provide the foundation for fostering capabilities, wellbeing and participation of people with disability, and promoting NDIS goals of choice and empowerment.

The nature of disability support work means temporary migrants may be exposed to levels of exploitation over and above that already experienced by the domestic workforce. While staff working in the homes of people with disabilities are vulnerable to isolation, a lack of collegial support and poor union representation, those on 457 visas will face additional barriers in raising concerns over pay, conditions and health and safety, because their visa and residency (as well as employment) depends on employers. The limited capacity of the Department of Immigration and Citizenship to monitor employers' compliance is well known.

In 2010, more than a third of non-professional disability workers in the non-government sector were casual, and more than half of employers reported that their non-professional employees were under-skilled. Upskilling is far from straightforward, as under the NDIS, it is unlikely that qualifications will be mandatory.

It remains unclear whether and how training will be paid for or delivered, and whether the cash payments allocated to consumers to direct to their preferred mix of supports are sufficient to pay decent wages and to backfill while support workers up-skill. Individual funding models can result in financial uncertainty for organisations, and raise challenges for planning a co-ordinated industry agenda to address recruitment and training needs.

Structural problems of low pay, low status, poor working conditions, and poor access to opportunities for skill development are disincentives for workers to remain in the disability industry. A strategic, national and collaborative approach to addressing these will be necessary if the high expectations of the NDIS are to be met.

Service users and their families take these problems seriously, frequently pointing to problems of unreliable, inconsistent support, and high turnover.

If the NDIS is to deliver on its promise of sector expansion and choice for consumers, it must address problems of workforce shortages, and associated issues of low pay, insecurity, low status, and under-investment in skill development.

Where people are highly vulnerable and or may live with Restrictive Practices it is essential that their supports are consistent, reliable and that the workers know and understand the person very well, and work within a 'right relationship' arrangement. If service providers are allowed to employ 457 visa workers this will be undermined, and inevitably there will be increases in applications for more types and frequents uses of Restrictive Practices, and more injury claims either by 457 staff or by the participants themselves.

5. Information, Linkages and Capacity

We do not want to see a return to block-funded individual supports, but many disability-focussed services do not lend themselves to a individual-user-pays approach. Referrals and linkages invariably are better provided by services whose core business may be elsewhere.

Referral and linkage services are no less important, but they are by nature brief, ephemeral, numerous, contextual and incidental.

People with disabilities and families often need to solve problems linked to disability, but they may be intermittent, or one-off fact-finding inquiries or other kinds of intermittent resource demands. It is not practical or cost-effective to incorporate such services into plans, even if a participant can foresee a need for them.

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