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Living with Disability RESEARCH CENTRE

Supporting inclusion of people with cognitive disability

Review of the Independent Person in the Victorian Approach to Regulating Restrictive Practices: ‘Its Great but Not Great in Practice’

Final Report – August 2025

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Glossary

Acronym	Term
APO	Authorised Program Officer
BSP	Behaviour Support Plan
CRPD	Convention on the Rights of Persons with Disabilities
DA	Disability Act
DFFH	Department of Families, Fairness and Housing
DSOA	Disability Support for Older Australians
IP	Independent Person
NDIS	National Disability Insurance Scheme
NPM	National Preventive Mechanisms
OPA	Office of the Public Advocate
OPCAT	Optional Protocol to the Convention Against Torture
OSP	Office of the Senior Practitioner
RP	Restrictive Practice
RRP	Regulated Restrictive Practice
SP	Senior Practitioner
SSR	Social Services Regulator
VCAT	Victorian Civil and Administrative Tribunal
VSP	Victorian Senior Practitioner

Executive Summary

The Client Voice research project was undertaken by a multi-disciplinary research team on behalf of the Victorian Department of Families, Fairness and Housing to review the role of the Independent Person (IP) and its function within the Victorian regulatory framework for the use of regulated restrictive practices (RRPs) within behaviour support plans (BSPs).

Research team

The Client Voice project was led by Professor Christine Bigby from the Living with Disability Research Centre, La Trobe University. Other team members were: Professor Shih-Ning Then (Australian Centre for Health Law Research, Queensland University of Technology); Dr Alison Brookes and Ms Charity Sims-Jenkins (Living with Disability Research Centre, La Trobe University); Ms Laura Hogan (Centre for Disability Studies, Sydney University); Dr Julia Duffy (Australian Centre for Health Law Research, Queensland University of Technology); and Ms Kathryn Bartlett (self-advocate lived-experience team member).

The project team were supported by a Stakeholder Advisory Group comprising representation from disability regulatory bodies, disability service providers, disability advocates, behaviour support practitioners, and family members of people subject to RRPs. A lived experience advisory group of three people with intellectual disability with experience of RRPs was also established and provided insights into and commentary on research data and findings.

Method

The project used qualitative interviews with people working within the regulatory space of the IP role. Interviews with 21 participants from disability advocacy organisations (5), senior and middle managers from disability service providers (including behaviour support practitioners) (10), staff from regulatory organisations or peak bodies (5), and one family member who acts as an IP for her son were conducted between November 2023 and July 2024. Interview participants were asked about their experiences of the IP role, views of its effectiveness, suggestions for strengthening the role, and ways in which client voices could be included and amplified throughout the wider work of the Victorian Senior Practitioner (VSP). Data was analysed thematically.

Findings

The IP role was highly valued for its potential safeguarding role for people subject to RRPs. However, the role was not reaching its potential or working as intended by the Victorian Disability Act (2006). Barriers to the IP role fulfilling its potential as a safeguarding mechanism included:

- Practical difficulties of locating a suitable IP for people subject to RRPs. This is largely reflective of the limited social circles and informal networks of people living with intellectual disability. Participants note that the IP role should be undertaken by someone who knew the person subject to RRPs well, and had an ongoing relationship with them.
- A lack of specificity with regard to the role, compounded by a lack of oversight, meant the role was too often reduced to a tokenistic “tick and flick” within the authorisation process.
- Challenges inherent in the role—for example explaining RRPs and rights to appeal to people with cognitive impairments—mean IPs require a suite of skills to ensure communication is effective and avoids evoking negative reactions. Expectations of the IP role may be unrealistic for people with more profound cognitive impairments.
- Difficulty of finding people to undertake the IP role with a broad understanding of the characteristics of people most likely to be subject to RRPs as these may be obstacles to building rapport, communication, and supporting a person’s preferences.

In addition to the skills of the IP to establish communication and rapport, specific disability support skills were identified as important for the IP role to meet its potential. These included:

- Understanding of regulatory and service systems and behaviour support practice.
- Familiarity with supported decision making to assist people to make decisions in response to their behaviour support plan and inclusion of RRPs.
- Policy expectations about furthering people's rights and the ongoing project of eliminating the use of RRPs.

Alternative behaviour support strategies that can be considered to ameliorate the use of RRPs.

To address some of these challenges participants advocated for comprehensive training in the above skills and areas, and access to timely advice and support for IPs from the VSP. Alternative models to the current IP role were also suggested by participants, including:

- Paid or volunteer advocates available for Authorised Program Officers (APOs) to draw from when locating an appropriate IP for a person subject to RRPs.
- A pool of recruited, trained, and supported volunteers available for people without someone suitable to act as an IP within their informal or social network.
- Professionalisation of the IP role, with it being undertaken by skilled disability service workers with a solid understanding of behaviour support, RRPs, the wider disability sector, and NDIS.
- Cross-organisational collaboration with disability support workers from one service acting as IPs for people using other services.

The Lived Experience Advisory Group participants emphasised the importance of people's involvement in decisions which impacted them, and the value of someone being available to assist them to articulate their preferences and advocate for them when necessary.

Recommendations

The research team make the following recommendations in response to the barriers currently limiting the safeguarding potential of the IP role:

- The establishment of paid people to act as last resort IPs when a suitable person for the role cannot be located within a person's social or informal networks.
- Clarifying the IP role, in particular the differences between the role and advocacy, ensuring that IPs know how to access advocacy for a person when needed.
- Clarification and strengthening expectations about the way the IP role is fulfilled and suitability for the role, including access to training in relevant skills to undertake the role.
- Make explicit the expectations about the relationship between a person subject to RRPs and an IP, including ongoing and regular contact to ensure that IPs are clear about the person's current situation, interests, and preferences.
- Provision of resources for training, support, and monitoring (oversight) of IP role by VSP.
- The VSP continue efforts at national and state levels to positively influence the quality of BSPs and behaviour support practitioners, including increased oversight of assessment and consultative processes undertaken in the development of BSPs, role of IP, and use of RRPs.
- VSP invest in a demonstration project through an NGO to build and support the development and maintenance of long-term informal relationships between people with intellectual disabilities and community members.

Introduction

This report describes the findings of a research project commissioned by the Victorian Department of Families, Fairness and Housing (DFFH). The project aimed to review the role of the Independent Person (IP), a role which is a key component of the Victorian regulatory framework for using regulated restrictive practices (RRPs) that curtail the rights of people with disabilities. The use of restrictive practices in Victoria with people who use services funded by the National Disability Insurance Scheme (NDIS) is regulated by both national and state legislation. Similar—but distinct—regulatory frameworks apply to adults who use Victorian disability services that are not funded through the NDIS. Appendix A (attached) provides a detailed description of the aims and approach to regulating the use of restrictive practices, and the relevant laws and policies.

Regulatory processes and the role of the Independent Person

There is a distinct role for the IP in authorisation processes for the use of RPPs in Victoria. An IP must be available to explain to the person with disability the proposed use of RRPs as part of a Behaviour Support Plan (BSP) and to explain their rights to a review if use of RRPs is authorised by an Authorised Program Officer (APO) or jointly by an APO and the Victorian Senior Practitioner (VSP).

The points below summarise the regulatory process for use of RRPs applicable to adults using NDIS services in Victoria. (More details are given in Appendix A together with the relevant sections of the legislation.)

- Disability service providers who implement BSPs that include RRPs must register with the NDIS Quality and Safeguards Commission (the Commission).
- An APO must be appointed by the registered service provider and approved by the VSP.
- A BSP must be prepared using a prescribed format and approach by a registered NDIS Behaviour Support Practitioner. This should involve a consultative process that includes the person, their family, relevant allied health professionals, implementing provider, and their carers.
- If a plan is going to include RRPs for the first time, an interim plan must be prepared and lodged with the Commission within 1 month and a comprehensive plan prepared and lodged within 6 months.
- The APO must ensure an IP is available to explain to the person the proposed use of RRPs and their rights in respect of the proposed RRPs.
- The APO authorises RRPs which then must be further approved by the VSP.
- If the VSP does not approve, the APO communicates this to the Behaviour Support Practitioner who revises the plan and again seeks authorisation.
- The approved BSP is uploaded to the Commission by the Behaviour Support Practitioner.
- The APO must provide the person with a copy of the BSP, the name of the IP and information about their review rights within 2 days.
- The APO reports monthly on the use of RRPs to the Commission, and within specific timeframes any unauthorised use of RRPs which constitute Reportable Incidents.
- Comprehensive BSPs must be reviewed every 12 months or when a change to the RRPs is made.
- The APO must ensure the IP is available to explain the BSP to the person, and any changes to the BSP when changes include more restrictive forms or uses of RRPs. This includes the right to seek further review of the change (for example, at the Victorian Civil and Administrative Tribunal (VCAT).

As indicated above, the IP role is primarily providing information and explanation to the person to assist in understanding a BSP and use of RRPs and advising the person of their rights. There are also provisions for the IP to have a more proactive role in safeguarding rights by ensuring all the legislative requirements are met in the preparation of a BSP that includes RRPs; the IP *must* notify the VSP if a person is not able to understand the proposed use of RRPs or if any of the requirements of either the Victorian Disability Act or those in the NDIS Act or Rules have not been met. They *may* also notify the Victorian Office of the Public Advocate (OPA) if either of these conditions occur (i.e. the person doesn't understand the plan or there has been a breach of the legislative requirements). The IP may consult with the VSP if they are concerned about the legislative requirements having been met.

It is not clear from either the Victorian Disability Act or the NDIS Act or Rules whether the IP must be involved in the development of the BSP. However, the NDIS rules for preparation of BSPs expect the involvement of the person and their support network, which potentially includes the IP, if they are family member or friend. Thus, the IP role appears to go some way towards meeting the NDIS practice standards that require a person to be involved in the development of a BSP. It is however equivocal if the role also contributes to the practice standard's requirement that the person be made aware of their rights to access an advocate.

It is not fully clear whether the IP role extends to explaining the use of RRPs to the person when plans are reviewed annually if there is no change to the use of RRPs. However, good practice would expect this, and a review might be construed as preparing a new plan, so it may be assumed IPs should be involved in reviews and thus annually with the person.

IPs are not decision makers, their role is not to consent the use of RRPs, as Victoria has an administrative approach to authorising RRPs. Neither is their role framed as that of an advocate or representative of the person's preferences or interests. For example, it is not expected that the IP take an advocacy stance if the person understands but does not agree with the use of RRPs in their plan. In such circumstances the IP role is to advise the person of their rights to ask the Victorian Civil and Administrative Tribunal (VCAT) to review the decision. Notably, it is the APO who must provide assistance in seeking such a review. Similarly, if an IP is aware that legislative provisions are not met in the preparation of a BSP and or the person does not agree with the use of RRPs, their role is to advise either the VSP or OPA rather than to act as an advocate for the person.

Who fills the IP role and the nature of the relationship between the IP and the person for whom a BSP is prepared is rather open. The only requirements are that the IP must not be associated with a disability service provider which is providing services to the person or have any responsibility for the development, implementation, or review of a person's BSP. This means the role may be filled by a wide variety of people who have informal (family, friends) or formal relationships with the person (advocate, service provider not directly providing services to them).

Methods

The project was designed to seek perspectives about the IP role from a cross section of people involved in the development and regulation of RRPs who had experience of the IP role, as well as people who themselves had been subject to RRPs. Data about perspectives were collected from individual interviews and through meetings of two advisory groups: a stakeholder group comprising professionals and family members, and a lived experience advisory group comprising three people with experience of RRPs. The project was approved by the Human Research Ethics Committee, La Trobe University (approval HEC23359).

Recruitment and data collection.

Participants were recruited by sharing information about the study across the networks of the VSP and the Living with Disability Research Centre, and a snowball approach of asking interviewees to

suggest others in their own networks who might be interested in participating. A total of 21 people participated in an interview. They were staff from advocacy organisations (5), senior and middle managers from disability service providers or behaviour support practitioners (10), staff working in regulatory organisations or peak bodies (5) and one family member. The interviews explored participants' experiences of the IP role, their views about its effectiveness, ways in which it might be strengthened and more generally about how client voices could be amplified throughout the work of the VSP. Most interviews were conducted using the digital platform zoom and lasted between 60–90 minutes. Interviews were recorded, transcribed and deidentified.

A stakeholder advisory group of 13 members was formed and met twice in August 2023 and June 2024. Members were family members or professionals with experience of the IP role and behaviour support, and recruited by invitation basis on advice from the VSP, and the networks of the Living with Disability Research Centre. The group provided advice on the research design and recruitment and commented on the interview findings and preliminary recommendations. Their views were summarised in notes of the meetings and formed part of the data set.

A lived experience advisory group took many months to recruit members by following up on contacts and advice from members of the stakeholder advisory group and the research team's own networks. Three women with intellectual disabilities who had experience of restrictive practices and IPs were recruited, and each met individually with a research team member between December 2023 and March 2025. All three women[1] live in group homes, one in metropolitan Melbourne (Lydia), and two (Jacinta and Renee) live in a large regional city. Meetings with each member were usually 30–40 minutes, held at the women's homes or in a café. Meetings sometimes included a staff member who knew the group member well and staff often volunteered information about the person's situation. The researcher did not interview staff about the person and time in meetings was spent building a relationship, talking about the project and their own experiences of RRPs and IP. A total of 32 individual meetings were held between December 2023 to March 2025 (Renee met 11 times, Jacinta met 15 times and Lydia 8 times). Notes were written after each meeting by the researcher which formed the data set for this advisory group.

Analysis

NVivo was used to support a thematic framework analysis. Interview transcripts and notes from the stakeholder advisory group were read and reread to identify the breadth of issues raised. Using a constant comparative approach, these were coded into topics, and categories within topics. Codes were progressively collapsed into themes which were discussed by the research team and refined. Initial themes were also discussed with the stakeholder advisory group. A similar process was followed to analyse the smaller data set from the lived experience advisory group. This analysis focussed on the perspective of the lived experience advisory group members and tried to distinguish this from information volunteered by staff. In the following sections we present the main themes from the study, illustrating them with extracts from the data.

Findings

Perspectives about IP Role — Valued for its Safeguarding Potential

There was unanimous support for the IP role as part of the authorisation process for the use of RRPs. The IP was seen as an important safeguard of people's rights, and seen as necessary given

[1] All names have been changed to ensure anonymity

the serious impact the imposition of restrictive practices can have on rights and wellbeing. Participants said about the IP role, for example:

> … it's that extra layer of safeguarding available and having someone come in and just promote the rights and entitlement for review for that person … it's pretty serious stuff restricting or infringing on a person's rights [Advocate 8].
>
> It's another safeguard for the rights of people subject to restrictive practices [Service provider 3].

The IP was seen as 'another set of eyes' that acted as a catalyst for better quality BSPs and decisions about the use of RRPs. Participants drew attention to the various ways that the role of the IP improved plans. This included ensuring plans were person centred, the network of paid and unpaid people in the person's life were involved in the plan, all options were considered before the imposition of restrictive practices, and the perspective of the person themselves was included in formulating the plan. Participants spoke, for example, about the IP role in ensuring the quality of plans:

> Having the ability to have multiple objective eyes over [a BSP] and to ask those questions and say "What evidence have you got? Is it enough?" Is it robust enough for us to be clear as a whole team with the person at the centre to say "Yes, they've been provided opportunities and options" … it allows for collaboration with the person with a disability and their independent connections that are outside of that paid responsibility, and so you're minimising those vested interests that other parties might have. It also allows for collaboration and questioning of the intention or the requirements of those restrictive practices, or just in general, the support model that is in place. [Service provider 12].
>
> I think the best thing is that when it's [IP] done really, really, well, it's a great example of excellent practice. We should be having conversations with people about things that affect their lives. We should be having meaningful discussions with people, utilising resources to support communication to ensure that where we are infringing people's human rights that there's a meaningful conversation about it [Service provider 5].

It was not only the presence in the process of another set of eyes that participants thought was important for safeguarding but also that the eyes belonged to someone committed to promoting and protecting the rights of that person at the centre of the plan. As the quote below suggests, while many participants thought it was really useful for the IP to know the person well, some thought the most important features of the relationship were commitment to rights, good practice and the elimination of restrictive practices:

> When it [IP] works really is when you have someone who really does know the person and are passionate about supporting the person in terms of eliminating or reducing restrictive practices. And [they] are very passionate around positive behaviour supports and what that means. I think it's definitely when someone understands the person, or if not the person per se, understands [and] has a passion for upholding human rights [Regulator or Peak body 20].

The safeguarding role of the IP was seen to revolve around ensuring the person understood why and what restrictive practices were being proposed, had a chance to voice their views about this and they were aware of their appeal rights if their views were overridden. Participants said, for example:

> I think the intention of the legislation is beautiful. I think it comes from such a great space for our clients to be able to ensure that they have good understanding of their restrictive practices, that they're provided with opportunity to have feedback to contest … to say "Hey, no! Actually, I don't agree" [and] that they're given that space to be able to feel supported and have their voice heard [Service provider 9].

All participants valued the potential safeguarding role of the IP, although some reflected that it should not be necessary in well-functioning disability services and regulatory systems. For example:

> I think, theoretically, if every party is playing their function well – so the Behaviour Support Practitioner, the implementing provider – that client voice should be throughout the development of the behaviour support plan. You shouldn't need a separate person to say, check that is all been done and that the person [has had it] explained to them. But we're not there. There's not the maturity in every player in the space at this point in time [Service provider 3].

Perspectives about IP Role – Not Working as Intended

Despite agreement about the potentially important safeguarding role of the IP, there was a strong sense among all participants that the role was not working as intended and was seldom as effective as it had the potential to be. These quotes are representative of the sentiments expressed by all participants about the way the IP worked in practice:

> The whole point is that everybody knows that it [IP] doesn't work, but it's a great idea. Everybody knows. [The] legislation's wonderful. It's just never good in practice [Regulatory or Peak body 11].

> … I don't think there's any argument whatsoever that in theory that is best practice and where we see it done really, really well, it's like "Oh, wow! That was great!" But it's just so few and far between that we do see it done that well [Service provider 5].

Suggested problems with the way the IP role was working related to practical difficulties of finding a person to fill the IP role, suitability of those who did fill the role, the lack of standards, oversight and support for the role, and the complex and challenging nature of the task itself.

Practical Difficulties – Finding an IP

A frequent practical difficulty was finding a person to take on the IP role. Participants indicated that many people they supported did not have informal social networks of family or friends with whom they had close relationships or were in regular contact. Indeed, some people did not have this type of relationships with anyone outside their immediate services. For example:

We've got a lot of people that came out of the institutions that don't have anybody around them. That's where it all fails. And how do you get [services] to actually build that circle of support around people because there's a lot of barriers to all of that as well. So, I guess, where [the IP] works well is when you actually do have a lot of good people that are around that person and everybody works together collaboratively, but that's very few and far between [Regulatory or Peak body 11].

> One of the challenges, I suppose, is that there's not always someone to perform that IP role [Advocate 14].

> … so many of our clients also don't have family or friends within their support network [Service provider 9].

The absence of an informal network around a person meant APOs had to search out potential IPs through extended networks looking for those with whom a person might have regular but perhaps not close relationships. As one provider said:

> I know that it's often a family member … sometimes it can be a neighbor, it could be a family member of another person who lives in the group home but happens to know the person with a disability for some time. Sometimes when people are really desperate it's been like, a hairdresser! [Service provider 7].

Identifying potential IPs was both a challenging and time-consuming task, and there was a sense that APOs struggled to have the resources to undertake it well. For example, service providers described what might be involved in identifying a potential IP:

> … for one of our clients, they [APO] are currently seeking an IP through their social networks. So, they do bowling, and they do different extracurricular activities … even though the client doesn't have family or friends that connect in that space they're trying to still seek someone who knows the client to be able to support [the process] to be done as well as possible. And so, they're putting in a lot of effort to be able to ensure that the client is being supported by someone within that space who knows them to a level … I think the hard thing within that though is finding someone who really knows the client [Service provider 9].

Practical Difficulties – Finding a suitable IP

Many participants suggested that the difficulties of finding a person to be the IP might mean compromises were made about who filled the role, and thus its effective performance. Concern about not only finding someone to fill the role but someone who was suitable was summed up by participants who said:

> The thing that I would be concerned about is, when it's not easy to find an IP … if it's a family member, [they] might not be the right person [Regulatory or Peak body 2].

> … there remains that issue of where a person doesn't have an [IP] who can it be, or where a person has an [IP], they may not be appropriate [Advocate 14].

Participants gave various examples of what they saw as an 'unsuitable' person carrying out the IP role. These included because they didn't know the person well, were not in regular contact with them, did not understand the IP role, or did not have skills or knowledge about the regulatory system and behaviour support practice. For example, participants said:

> … oftentimes it's [IP] being done by somebody who hasn't met the client, who doesn't have any idea about how to communicate well with a client in terms of how to ensure the client receives the information to get that feedback, those sorts of things [Service provider 9].

> … you might find somebody, and you have a chat with them, and they will do it [IP], but they're very long-distance … we've got families where they'd be living in another state and that kind of stuff as well [Regulatory or Peak body, 11].

> … rather than understanding their purpose is to communicate what is being proposed and to ensure that all the requirements have been met … they [IP] see it as a guardian signing off on behalf of the person. That message of what's the intended role of communicating the proposed restrictive practices to the person has not been well conveyed or well understood … There's a lot of characteristics that you need [as an IP] which is very hard to find, because the amount of time that as an implementing provider we've got to spend with that person [IP] … we can give them information that's been made readily available, like the Independent Person Toolkit, but a lot of the time they don't read that [Service provider 3].

Related to not fully understanding the role as upholding the rights of the person, many participants pointed to conflicting interests they had seen arise when a family member had taken on the IP role. They said, for example:

> … many [IPs] who are family members who don't really know what a restrictive practice is and sometimes actually think it's the best thing for their son or daughter and don't want it faded out. Or sometimes [the OP thinks] "they're not going to understand what I say anyway, so I'm not going to have that conversation" [Service provider 6].

> You might have family members who actually think there should be more restrictive practices in place and aren't actually in agreement with what's been proposed by the behaviour support practitioner, so are they the best place to go through that conversation with the person? [Service provider 5].

> I think from a family's perspective, I think there's an inherent conflict there as well, because there can be a fear for families not to want to lose services. So, if an organisation is saying they have to use a restrictive practice to keep the person safe or not, there is the potential for there to be that fear for the family member to not object because they don't want to necessarily lose services or they are grateful, thankful for the services [Service provider 3].

However, the unsuitability of family members per se for the IP role was not as clear cut as these participants seem to imply. Many participants saw the value of family as they often knew the person better than anyone else involved with them but also saw the benefit of involving someone who could bring a more independent perspective than families might. One advocate said for example:

> What I worry a bit about too is if it becomes a bit of a binary here, if it's all family or all someone independent outside of the person. I would really want a model where families are included as well and where whoever is doing the IP role has some skill and education around talking to people [Advocate 16].

Participants suggested that advocates employed by advocacy organisations such as VALID or Leadership Plus sometimes filled the role of an IP if no one else could be found. Several problems were identified with this approach. First, client-advocate relationships were likely to be short term, with no expectation of the advocate continuing to fill the IP role and building a long-term relationship. Second, advocacy organisations were not funded to take on this role and it was an additional demand on their limited resources. Third, the use of paid advocates was contrary to the perceived intent of the IP as an unpaid informal relationship. Participants said, for example:

> We often get referrals from APOs for us to act as the IP for someone who has no informal supports that can do that on their behalf … We do that very limitedly, simply because we have

> limited time to do that. We engage with them usually one-off: we have a one-off meeting with the person, sometimes it's online … if we're far away, which is less than ideal. We try to make it in person wherever possible … It can be a difficult experience for them [the person] because we are a stranger coming in … a lot of the time people do not know what a BSP is when we come to talk to them … [Advocate 18].

> … obviously, that's [IP role] not something they [advocacy organisations] get paid for … And so it also means the APO is putting additional pressure on that one organisation to say "Hey, we've got these clients that are cropping up all the time that need IP." So, yeah, it's placing an additional burden on them [Service provider 9].

Lack of specificity and oversight of the IP role

The difficulties of recruiting suitable people as IPs, particularly finding people who had knowledge about the role, service systems and behaviour support practice, were compounded by the design of the IP role. Many participants suggested that the requirement for the APO to 'ensure availability' of an IP, and for the IP to 'explain' proposed RRPs to the person were rather vague and unspecific. In turn this meant the IP role in the authorisation process easily became tokenistic – something that could be completed and ticked off without any regard to how it had been carried out. Participants explained the potential for a 'tick and flick' approach was heightened by the absence of any monitoring or oversight, beyond the APO reporting the name and contact details of the IP to the VSP. Participants pointed to an absence of requirements to record how the role was carried out, to demonstrate that the IP understood their role, that the IP had undertaken any training about the role or had the skills or time to undertake it. Participants said, for example:

> [T]here's no minimum standard at all for it … there's no way of verifying what's said and how it's said, and I wouldn't be surprised if people just signed their name and didn't do anything with it to be honest [Regulatory or Peak body 15].

> … we're asking them [IP] to have this conversation with a person about the restrictive practices within their plan and there's no education for that person [IP] to have that discussion other than a Toolkit that no one takes the time to read … we don't know if they've [IP] had the conversation and how they've had the conversations, how the person received that information and whether or not that person was provided the opportunity to take something to VCAT or not. That is all just a big grey "Who knows?" But we know that someone's available and we can tick a box [Service provider 5].

> It's a tick a box! So, you're legislatively required to put the name that an IP has been consulted – I have found that year on year, a name has been put into the system as a person having performed the role. And when you unpack it, no they haven't. They may have at a point in time years ago, and then it's been carried over … [Service provider 3].

Despite the lack of oversight, several participants suggested that some organisations took the role seriously, trying to ensure it was carried out effectively by seeking information about how it was performed, and training or supporting IPs. Similar to locating suitable IPs this was a resource intensive task. Participants said, for example:

> So, where the organisations take the initiative to seek out information as to how that conversation went themselves, that can be beneficial to see the outcomes, but that's hard … that's a big task [Service provider 5].

In contrast several other participants suggested that some organisations did not take the role seriously:

> There's not a robustness in what a clear engagement looks like for that IP. So, it could just range from them just saying "Oh, there's a [BSP] that we're renewing now. Is that okay?" Some organisations don't even do that … I support a woman who's in her 50s. And she has had restrictive practices for a long, long time … I don't believe that the organisation is going through a robust IP process. They list her parents as the IP, but I would nearly guarantee that they haven't actively educated them around what those restrictions are, and what impact that has on their daughter [Service provider 12].

Challenging and potentially unrealistic nature of the task

Participants referred to the difficulties of explaining RRPs to people with cognitive impairments. They suggested some people with disabilities found it hard to understand BSPs and what RRPs were, and for others past traumatic experiences of restraint could mean discussion about such topics was likely to evoke negative emotional reactions. As interviewees said:

> Some of them [conversations about RRPs] could trigger behaviours of concern in and of themselves … That's a really tough conversation for someone with a disability to be a part of as well, which is why often a family member won't even actually broach that conversation [Service provider 5].

> … we've written all the legislation for "disability". I think when you write these broad sweeping things with the assumption then at this end people can negotiate or whatever … they have to start recognising that intellectual disability is different. It's not the same to be a Kurt Fearnley or Natalie Wade as it is to be someone who lives in a department house with a BSP. And our legislation doesn't make that distinction explicit [Service provider 10].

> … I think I'd probably go a little bit further and say that there would be many individual people with disability, subject to restrictive practices, who do not have the capacity to understand anything to do with restrictive practices being used on them [Regulatory or Peak body 15].

The only family member of a person who had been subject to RRPs who was interviewed echoed these concerns pointing to both the comprehension and communication difficulties she encountered in being her son's IP and explaining use of RRPs to him. She said about her son:

> I can't have that discussion with [him], there's just no cognitive ability to understand that type of conversation. We've got about 20 signs that are very, very urgent needs like food and drink, and shower, and car, and that's really as far as his understanding is able to be taken to … [Son] does not have his own voice, [he] cannot speak, other than with behaviour, and I have to be his voice, and I have to be his IP as best I can [Family member 17].

The difficulties in explaining the proposed use of RRPs are potentially mitigated by high quality BSPs where, for example, the person and others in their lives have been involved in formulating a

plan and communication strategies for explaining the plan to the person have already been identified and used. In contrast, however, many participants commented on the deteriorating quality of BSPs in the last few years, which compounded rather than mitigated the difficulties of the IP role. Participants gave examples such as limited time available to practitioners to develop plans that led to failure to involve people in the process, the increasing length and complex nature of plans which made them difficult to understand, and the lack of resources to present plans in ways that were understandable to the person. They said, for example:

> … it's all about funding. How many hours did the NDIS provide you to support the person … there's often very few hours, if any, to focus on how to support the individual to understand what's going on … the funding is not there or the experience and ability to create a document to help a person understand what it is. Is it a video that makes it best for them? Is it real pictures? [Are] there too many photos on the one page? [Service provider 13].

> So, you write a good [behaviour support plan], it's a good [person-centred plan] and it should be useable [but often], no staff member can read … nor can they apply it [Service provider 10].

None of the participants could recall an instance where a person had appealed to VCAT about the imposition of RRPs. Many thought this was because the appeal process was complex and daunting, particularly for people with cognitive impairments which meant they may not fully understand the process or the proposed use of RRPs. They said for example:

> I've never had anyone take up an appeal in all the years that I've worked in the sector … I've worked predominantly with people with more moderate to severe intellectual disability. And those individuals don't necessarily have the ability to understand their right to appeal or understand the restrictive practice, to be honest. And I think that leads to why there aren't any appeals and why there aren't any objections [Service provider 3].

> … The only process is that [a] person could be supported to make a complaint to their APO who's then responsible to bring that to VCAT, and then VCAT make a decision whether or not that restrictive practice is appropriate. What an immense and lengthy thing for someone to go through! Who, first off, doesn't understand why the restrictive practices are being implemented, and they may not even know they have an APO, and they don't know what VCAT is [Advocate 18].

Several participants also suggested attitudes of either IPs or APOs may influence the take up of appeal rights and gave examples of the different ways in which these might be presented to a person to either discourage or encourage them to pursue an appeal:

> So, the conversation inevitably is "Hey, we're going to implement this restriction on your life and if you have a problem with that, then there's a big lengthy, legal process that you don't understand that you can enact. Would you like that?" [Service provider, 5].

> Are you really okay with this or not okay with this? And these are your rights, you can say no, you can go to VCAT and this exists. You can get potentially a lawyer to represent you at VCAT and we will [help you with this] [Advocate 16].

Participant Perspectives on Specifications for the IP Role

As already mentioned, many participants identified that the IP role may not work as intended because of a lack of specificity about who should fill it and how it should be carried out, and the 'unsuitability' of some who filled the role who were often unclear about it or lacked the knowledge and skills to carry it out well. Participants had ideas about what constituted suitability for the IP role and the specifications there should be. Suitability was seen to be multi-faceted, revolving around the nature of the IP-person relationship and the knowledge or skills required by an IP about the role, regulatory and service systems, behaviour support and rights of the person. This section brings together participant perspectives about components that should be included in a clearer specification of suitability for the role.

Relationship and knowing the person

All participants agreed about the necessity for the IP to have good rapport and a trusting relationship with the person. Ideally, they thought this meant an established relationship and knowledge about the person but alternatively having time to establish a relationship and get to know the person. As participants said:

> I mean utopia would be somebody that's in that person's life very consistently on a personal basis, right? [Regulatory or Peak body, 11].

> … what we do really want in practice, you need time, you need to develop rapport with the person. Preferably a trusting relationship [Advocate 14].

Once established, many participants considered a need for continuity in the relationship between the IP and the person to avoid a recurring cycle of establishing very short-term relationships every time IP involvement was required, as often occurred when advocacy organisations filled the role. For example, one participant talked about the drawbacks of the common practice of students on placement at advocacy organisations filling the IP role:

> … that social work student is not going to be there. So, it means then we're still going through the process again, and it's still not actually meeting what the IP legislation is supposed to be there for, which is to ensure that the … IP is really involved in the client's life ... [Service provider 9].

Participants identified the type of things an IP should know about the person such as their past experiences, current situation and ways of communicating. Talking about what was important for an IP to know about a person, participants said for example:

> … knowing how they communicate, consulting with them, and that doesn't mean having a sit down in conversation and saying, "Oh hello [Name], when you start to dysregulate, I'm going to sit you in a corner with a weighted blanket on and are you happy about that?" It might be looking at building up a picture of that person and their reactions to things, what makes them happy and what doesn't … [Regulatory or Peak body 2].

> … we need to really sometimes spend the time with the person to try and understand them. You know, just the slowness of speaking. But it might also be asking the staff "When is this person happy? When are they unhappy? Do you know, like what actually happens?" [Advocate 16].

More general knowledge about people subject to RRPs

In talking about what IPs should know about the person they supported, participants alluded to the characteristics that people subject to RRPs often shared in common which they thought were important to understand in communicating and building rapport. They included characteristics such as difficulties understanding and communicating or expressing their own views, experiences of trauma and stigmatisation and having few close social connections. Participants said for example,

> [IP needs to be someone who] understands communication issues with [people with cognitive disability] because I would take a stab that most of the people who are having some sort of behaviour support with restrictive interventions have some communication challenges. I don't think there are many that don't. And so having someone who has got some pretty high-level skills in that area … [Service provider 7].

> [people subject to restrictive practices are] probably more likely to have broken-down relationships … So, I just think it's really tricky then to develop a relationship enough to explain something and to feel that person trusts you … and they understand their rights … they don't have that same sense of, I suppose it is entitlement and privilege to say "I don't like that and I won't do that." They just feel they don't have that. I think there's a lot of stigma as well and perhaps it's overwhelming … If you're explaining something to someone and saying, this is your right, but are they just agreeing? Because they don't feel very empowered and they also want to please the people they're relying on [Advocate 1].

> … it may take a number of visits for [communication] to happen. Because the person is not engaged or it seems like they're just saying yes, but they don't understand it. That's not for us to then say "Well, they said yes, so therefore they understood." Where actually you might need to go back and see if the answers are the same again … So, it's trying to really get an informed answer rather than just what the person may have responded to. Because they don't want you to be there, so "I'm just saying whatever you need [to hear] because the sooner I say that the sooner you go and I can go back to what I want to do" [Service provider 13].

Some participants suggested that skills in supported decision making were also important for IPs as they were supporting the person to decide about how they thought about the proposed RRPs. They said for example:

> Because part of it [IP] could be seen as a supported decision-making role. You might be supporting the person, or trying to support the person, to make their own decision in relation to that restrictive practice … You need to have skills and guidance around what is supported decision-making [Advocate 14].

The implication of the foregoing extracts from participants is that IPs should have a broad understanding of the likely characteristics of people who are subject to RRPs as these create obstacles to building rapport, communicating and supporting expression of a person's preferences. Such knowledge might assist in tailoring their approach to getting to know and communicating with the individual they were involved with as an IP.

Knowledge about regulatory and service systems and behaviour support practice

Most participants thought IPs needed to have at least a rudimentary understanding of the regulatory system for the imposition of RRPs, including how the process was expected to work, roles of various players (such as behaviour support practitioners, APOs, the VSP, and the Commission), policy expectations about furthering rights and eliminating use of RRPs, the purpose of BSPs, the rationales they should expect to see in BSPs about the use of RRPs, and types of behaviour support strategies that should be included in plans. They said for example, IPs should know about:

> … types of scenarios that you might be interacting with. What's a restrictive practice, why someone might be on it, might be subject to it … understanding the risks, the benefits, the alternatives to the restrictive practices [Advocate 14].

> … really good knowledge of behaviour support, restrictive practices, [Service provider 7]

> fairly good understanding of what those [other] roles are doing, and the methods they're using, the multi-element approach, all of that [Service provider 4].

> … information regarding what a behavioural support plan is, what it entails [Advocate 18].

Importantly too participants thought that IPs needed a clear understanding of the IP role and purpose in the regulatory system. As one participant said: "what your duty is and how do you do it and those kinds of things" [Service provider 5].

Training and support

All participants thought that training should be available for IPs about the types of knowledge and skills mentioned in the sections above, as well as their role in the system. Also, that the training should be more intensive and comprehensive than the existing Toolkit and should be complemented by access to timely advice and support to IPs as they were carrying out their role (the Toolkit is no longer available on the VSP website). Participants said for example:

> If it's going to be a genuine element of safeguarding, then the resourcing is about a particular prescribed group of people to do that role, or the people who agree to be the IP need to go through some sort of basic education I suppose about what your duty is and how do you do it and those kinds of things [Regulatory or Peak body 15].

> I think there needs to be training sessions, modelling, coaching, like let's get back to education and get people truly understanding what's required in these conversations rather than assuming that the Act and Toolkit will mean that people know how to do this well. I think there is a role for the VSP to actually play, like they do in educating APOs and developing workshops around that. Some further workshops around the IP process should sit in their scope too [Service provider 5].

> … a helpline, or a help email, from the VSP's office where they [IP] go for information for guidance, or if they have any queries or concern … It [BSP] often comes to you quite last-minute, and so if you have any queries, concerns, or problems, or simply don't understand what your role is meant to be, you need more immediate support, so maybe a process document written in Easy English, so that it's acceptable for everyone, that explains the role of an IP, what their responsibilities are, and includes where they can go to for help and support.

> Because someone's mother had never thought that they needed to do this and maybe haven't been appropriately told what the implications are of this document [Advocate 18].

Participant Perspectives About Approaches to Filling the IP Role

In addition to the need for clearer specifications about the IP role in terms of the expected relationship to the person, skills, knowledge and training required mentioned in the previous sections, participants suggested various approaches to tackling the problem of finding suitable IPs. These are categorised and summarised below using extracts from the data. The pros and cons of some are considered further in later sections that discuss the findings of the study in the context of the literature.

Using paid professionals or volunteers as IPs

In talking about alternative approaches to finding IPs many participants assumed a close affinity between the IP role and that of an advocate, suggesting either paid or volunteer advocates could fill the IP role. These two extracts capture the most common alternatives proposed:

> In an ideal world, I'd like to see a massive expansion of our advocacy services across the state. I think that we should be investing heavily in developing advocates, who should not just be being involved retrospectively when there's a problem but being able to be proactively [involved] – I would argue that basically everybody with a disability should have an advocate, that is separate to their family and separate to the people who provide service. And I think that in an ideal world, then that person would have a whole of life picture. And there'd be some people who didn't need a lot, where they [advocate] could just come in on occasion, maybe have a few meetings. But in preparation for their planning meetings, in preparation for any major changes, in preparation for a [behaviour support plan] or other plans, to be able to get an independent voice that wasn't thinking about the money, and wasn't thinking about the fear of the Commission, would be amazing … So, you'd have paid advocates who work for your really complex matters, and paid advocates who were training and running groups of volunteers [Service provider 10].

> Wouldn't it be great if there was funding to enable a well-trained pool of independent advocates to be having these [IP] conversations with people with appropriate resources to do so and reporting mechanisms to demonstrate it's being done well [Service provider 5].

Some suggestions did not necessarily see the IP role as synonymous with advocacy but similarly proposed that volunteers could take on the IP role. They envisaged a pool of volunteers ready to be matched to a person if no person suitable for the IP role could be found. A pool of volunteers and matching process could be achieved through the creation of a program that recruited, trained and supported volunteers (similar to the Victorian Independent Third Person or Community Visitor programs). Participants explained, for example:

> It [the IP role] could be performed by volunteers but that they be trained volunteers that are – like a similar program, I suppose, to the Independent Third Person Program … Or the Community Visitors Program … that would mean at the very least some people who wouldn't

> have an IP could get access to one. And if you've got a volunteer pool that's supported and trained, and available you might be more likely to get an IP when you need one [Advocate 14].

Proposing a similar approach, one participant suggested that disability service providers through for example APOs could be involved directly in recruiting volunteers or finding local organisations which might take on the task:

> … looking at how to build up a pool of IPs … that will be developing relationships with the local area, so whether it's service groups like Rotary or Lions, or people … passionate around supporting, or upholding human rights, or just engaging with others … There's a lot of people that don't work in the sector that are very passionate around supporting people with disability … Which means going out into the community and explaining what the role is and inciting some sort of passion and people understanding what it [is] and just bringing them along and skilling them up [Regulatory or Peak body 20].

A variation on these suggestions, but which expanded and professionalised the IP role, was to fill it with an independent and skilled professional who worked with the person and made judgments about the appropriateness of using RRPs. One Service provider said, for example:

> I think a much better approach would be to have a truly independent person who understands behaviour support, understands restrictive practices, understands [services] and NDIS as well, but is allocated to a person who isn't able to make their own decisions. And spends actual time with that person to get to know them and then can go, "Yes, I agree for this restrictive practice but this one I don't think we should be doing". That's the ideal, really … [Service provider 7].

This suggestion seems to be moving away from the current IP role as explaining and advising about rights and towards a professional IP as a decision maker and the final arbiter of whether RRPs should be imposed.

Cross-organisational collaboration

Another approach to the difficulties of filling the role of the IP was for a professional from another disability service provider to take it on by means of reciprocal agreements between organisations. Participants said, for example:

> It would be interesting to know whether or not you could … get some cross-organisational collaboration. So, people who work in the sector, who are, say, frontline leaders within the disability space, who understand [behaviour support plans], who apply [behaviour support plans] could perhaps do that [IP role] for an organisation that they have no attachment to [Service provider 10].

> … so, you might have registered provider A that's in [small town] and registered provider B that's in [a nearby town], and so they swap. So, they'll have persons that work for the [nearby town] organisation act as IP for the [small town] [Regulatory or Peak body, 21].

One participant suggested that APOs have the necessary background, knowledge and skills to take on the IP role for other organisations. They said:

> … being IPs for people we support because we have the knowledge, we have the [APO] background, we know about reduction elimination, we know the right questions to ask [Service provider 6].

Some participants were unsupportive of this type of cross organisational collaboration in filling the IP role suggesting that it might lead to collusion and BSPs may be approved by one service to facilitate swift approval of their own plans by another service.

Perspectives of Lived Experience Advisory Group Members Subject to RRPs

This section pieces together the experience of each lived experience advisory group members about the IP and the proposed use of RRPs.

Lydia

From Lydia's perspective the first she knew of the proposed imposition of an RRP that would restrict her smoking, was when a support worker told her she had to stop smoking. It was not clear that such restrictions had been authorised, were part of a BSP and if so whether an IP had been involved in this process. However, when Lydia made it clear she did not want to stop smoking, the service provider found an advocate to support her to pursue her objection. The issue was resolved, apparently without reference to external bodies such as the VSP, OPA or VCAT and there was no follow through of the proposed restrictions. It was difficult for Lydia to talk about this issue and became visibly upset whenever she brought it up. One of the things that she had found particularly upsetting was that other people wanted to tell her details about the negative impact of smoking. She said she already knew it was not good for her health and had asked to stop being told about this as she still wanted to continue smoking.

In Lydia's case it may have been that a service manager had decided to restrict her smoking following health related advice, and the decision had not been included in a BSP. Nevertheless, for Lydia this was an instance of other people deciding what should happen for her and she was adamant that she should be involved in any decisions about her. She thought the "the offices" [government and private services] don't listen and should learn from places that do.

Jacinta

Jacinta's father acted as her IP. She described them as having a close relationship and being in regular contact. Hower, she said on several occasions that he was "too old and worn out to look after all the stuff for her". From her perspective, the service manager (house supervisor) would be a better option for an IP, as she trusts him and sees him more than her father who she sees once or twice a year. Jacinta would like her counsellor to be involved in any decisions as the counsellor knows what Jacinta wants and is a good advocate for her both within the accommodation service and with other service providers.

Jacinta also talked about her counsellor as someone who can help with her feelings, explaining that she had worked out a range of strategies with the counsellor to help when she is 'angry'. For example, if she is prompted to call her counsellor, she can reduce her self-harm and is also nicer to others.

Jacinta is not happy about the medication she is taking which was changed recently and means she has begun menstruating again. She was not consulted about the change and has not been able to get anybody to explain it to her. She says that everyone should explain things and not just do them to her.

In Jacinta's case the psychotropic medication she takes is possibly a form of chemical restraint although she is under the impression it is for a physical condition.

Renee

Renee's cousin is her IP. She doesn't remember him but does talk about other members of her family. One of the staff members who has worked for 8 years in the accommodation service where Renee lives said that they had "never laid eyes on him." Renee did not get on with some of the people she lived with and was worried about the impact of their behaviour on her. Sometimes Renee's preferences are not prioritised, and decisions are made about other people in the house that affect her. She would like to have someone 'on her side' to tell her what was going on rather than things just being decided.

It was not clear whether Renee was subject to any restrictive practices or whether the IP had explained these to her. Nevertheless, she had a strong sense that she was not involved in decisions that affected her and this was not ok.

All three lived experience advisory group members expressed strong views about being involved in decisions about their own lives and felt they were often excluded from these or 'bossed' around by others. They all talked about small and 'big' things in their lives that they would like to change and felt they got little or no support to achieve such changes. For example, Jacinta believes she would not be 'allowed' to make small decisions about the house where she lives such as the colour of her room as she was not allowed to choose the house. All three would prefer a different living arrangement. Overwhelmingly, the women explained that people should not plan and decide things about them without their being included.

They all valued having someone to help them articulate their preferences, talk through options and advocate for them. Renee for example, wanted someone else to talk to "the bosses" a term she used often jokingly to refer to support workers.

The experiences of all three of the lived experience advisory group members reinforced the valued intent of the IP role to ensure any proposed RRPs were explained to the person, and they had the opportunity to voice any concerns. Members talked about many experiences in their lives including that of RRPs where they were not included in decisions that affected them. They identified a range of people, including their own service providers and external advocates, as being important in helping them to 'stand up' for themselves.

Summary of Findings

There was a strong view among all participants that the role of the IP has the potential to fulfill an important function of value to people subject to RRPs in Victoria. There was also unanimous agreement that the potential of the IP role was not being fulfilled, and it was not working well. Moreover, at times, the requirements to name an IP as part of the authorisation process might be met but the role was only enacted in a tokenistic manner.

This was a qualitative study, so we cannot make claims about the scale of the problems with the IP role in practice. However, there was considerable agreement from a diversity of participants about the problems, and very few examples of the IP role working well or as intended. Notably the absence of data from the VPS about who filled the role and how it was carried out or about those subject to RRPs compound the difficulty of understanding the extent of the problems.

The main problems with the way the IP was working were:

- Difficulties filling the role per se and filling it with suitable people.
- Lack of specificity and oversight of the IP role.
- The challenging and potentially unrealistic nature of the task.

Proposals about what should be included in more detailed specifications for the role were suggested and approaches to filling the IP role for people without social networks.

The lived experience advisory members were all clear that decisions about them were often made without their involvement and pointed to the importance for them of having an advocate or someone to support them to stand up for themselves.

Discussion

The IP is part of the Victorian process for authorising the use of RRPs. This process is administrative, and it does not require a person's or a guardian's consent for the use of RRPs. Rather it relies on professional judgement and expertise, first of the behaviour support practitioner and then of the APO and VSP, to weigh up tensions between protection of individual rights to autonomy and safety of the person and others. The IP role aims to ensure inclusion of the person's perspective or 'voice' before RRPs are authorised, provides an avenue to report failure of providers to comply with authorisation processes (to VSP or OPA) and for a person to challenge the use of restrictive practice, through recourse to VCAT. The study identified various ways in which the IP role is not working as intended. The next sections consider some of the reasons for this that can inform strategies to improve its functioning.

Reasons the IP is not working as intended relate to its design: who is expected to fill the role, the types of tasks expected of the role and the lack of resources dedicated to the role within the regulatory system. In some respects, the IP role is not a good fit for the people it was designed to support or the tasks expected of it. In simple terms:

- The IP is expected to be an informal network member of a person subject to RRPs, but many people subject to RRPs are socially isolated and do not have strong informal networks.
- The task is to explain intentions about the use of RRPs within the context of often complex behaviour support plans to people subject to RRPs, but some of those people have significant comprehension difficulties and high communication support needs which stand in the way of understanding these things.
- Significant knowledge and skills are needed to do the role well, but it is undertaken by volunteers with limited training, support or oversight.

Social isolation of the people for whom the IP role was designed

The IP must be independent of any of the service providers paid to support the person. Though not explicit in the legislation, the design of the IP role appears to assume that it is filled by someone with whom the person has an existing informal relationship (i.e. the IPs knows them prior to acting as an IP), rather than someone in a paid relationship.

There is a significant body of literature indicating that people with intellectual disabilities (the group most likely to be subject to RRPs), particularly those living in supported accommodation services, are often socially isolated and do not have strong informal social networks, beyond peers with intellectual disabilities or family. Furthermore, that some may not have strong relationships with family or have families who are ill equipped to carry out the role.

The evidence for these assertions is found in academic literature (see for example, Bigby, 2008; Forrester-Jones et al., 2006; Stancliffe & Hall, 2023) and government reports such as the Disability Royal Commission (CoA, 2023a) and the NDIS Review (CoA, 2023b). It was also evident from the data collected in the present study. Given this, the difficulties recruiting IPs from the informal networks of people subject to RRPs should not be surprising, as many of this group do not have informal networks from which to recruit.

People with intellectual disabilities continue to have poor informal social networks despite more than two decades of progressive disability policies at both national and Victorian state levels that have sought to further their social inclusion. Initiatives and innovative programs to build social connections have taken many forms over this time, for example Leisure Buddy and Gig Buddy programs, Key Ring, Befriending programs, Citizen Advocacy, programs to support volunteering and community participation and Circles of Support (see for example, Amado, 2014; Araten-Bergman & Bigby, 2022; Bigby et al., 2018; Bigby & Anderson, 2021; Bigby & Araten-Bergman, 2018; Bigby & Wiesel, 2019; Bould et al. 2018; Citizen Advocacy, u.d.; Craig & Bigby, 2015; Fyffe & Bigby, 2008; Fyffe & Raskin, 2015; Harlan-Simmons et al., 2001; Petroutsou et al., 2018; Stancliffe et al., 2015). While many of these programs have been successful on a small scale they have seldom been implemented at scale. The literature suggests they require intensive and skilled staff resources, and an ongoing approach focussed on maintaining as well as forming social connections.

In light of this literature, it is also not surprising that the present study found that APOs struggled to recruit IPs for those without strong networks, and that many claimed they did not have the time, resources or skills to do so. In the current NDIS context, it is not clear which if any disability support organisations have a mandate or funding to develop informal social networks of isolated people with intellectual disabilities. The social isolation of people with intellectual disabilities poses problems beyond recruiting people to the IP role in terms of negative impacts on the wellbeing of people subject to RRPs that requires concerted attention (see later section).

Suggestions for Action about Filling the IP Role – a last resort IP

The known social isolation of many people with intellectual disabilities and knowledge from the literature about the intensity and challenges of building social connections should inform approaches to tackling the difficulties of finding suitable IPs for the role. Filling the IP role is unproblematic for those people with strong social networks, however if the IP role is to work well the difficulties in filling it for people without such networks and for whom APOs cannot easily identify someone must be addressed. We suggest a *last resort* option should be established with capacity to fill the role quickly (given the time frames for preparation of interim and comprehensive BSPs (1 & 6 months) with someone who has the pre-requisite knowledge and skills to carry out the role, and who can develop an ongoing relationship with the person. Criteria would need to be developed for APOs to access a last resort IP. This might be for example, evidence of unsuccessful attempts over several weeks to locate a suitable IP in the person's informal networks.

Current last resort options appear to be finding an advocacy organisation to take on the role or simply the APO naming a person for compliance purposes. Both have drawbacks. Advocacy organisations lack resources to fill the IP role on a continuing basis, and simply naming an IP to tick off the requirements leads to tokensim rather than safeguarding. Our data and the literature discussed above also suggests that APOs or disability service providers more generally are not adequately resourced to search out last resort IPs, as this is a skilled and resource intensive task.

Study participants proposed a range of ideas for last resort options which are described earlier. These revolved around establishing a pool of paid professionals or volunteers who could act as the IP or through cross organisational collaboration whereby staff from another service provider unconnected to the person filled the IP role. All such options would require resources and a scheme or program to be established. The following sections briefly consider the pros and cons of various last resort options bearing in mind the evidence canvassed above about initiatives to build social connections for people with intellectual disabilities.

Establish a pool of volunteers

This might be a scheme similar to Citizen Advocacy, Gig or Leisure Buddies which develops a pool of volunteers willing to take on the role of IP and build an ongoing relationship with the person subject to RRPs. The scheme's functions would include recruiting, screening, training volunteers, getting to know each person who requires a volunteer IP, matching volunteers to people, and then supporting and monitoring the work of volunteers. A scheme may also reimburse volunteers for travel or other expenses. It would require funding for staff to coordinate the work. The scheme could be a standalone initiative or one of several programs managed by an organisation. Potential auspice organisations might be community support or community development services or advocacy organisations.

The pros of this option are the potential for the development of an ongoing informal relationship between the volunteer IP and the person, surety that the IP has had training and ongoing access to support and advice. The cons are the scale of resources required for such a program to function effectively, the length of time it might take to match a volunteer to a person who requires an IP, and uncertainty and difficulty recruiting and retaining sufficient volunteers. A scheme of this nature might be costly and have only a narrow focus, and while it might tackle the immediate difficulty of recruiting IPs, resources may be better utilised in a scheme with a wider aim of building and maintaining informal social relationships for people with intellectual disabilities who do not have any (see later section).

A hybrid of this volunteer option might be for a scheme to include staff who could also act as IPs on an interim basis to meet required timelines for BSP development with a view to handing over to a matched volunteer when a suitable one is available.

Establish a pool of paid people to act as IPs

This might be a scheme similar to the Department of Social Services (DSS) supported decision making pilot, where organisations are funded for one or more paid staff fill the IP role for a person in a timely manner on a potentially ongoing basis. Like the option of a pool of volunteers such a scheme could either be stand alone or managed as one of several programs offered by an organisation.

The pros of a scheme like this are quick and guaranteed access to a last resort IP when needed rather than waiting for a volunteer match, greater certainty and cost effectiveness than recruiting, training, matching and supporting volunteers, the potential for continuity in the relationship between the last resort IP and the person, and concentrating the last resort IP role among a small number of paid staff. This would build a group with significant expertise who may also act as a resource to other IPs. Over time the paid IP may be replaced by someone with an informal relationship if more comprehensive schemes to build informal networks were established and successful. There are few cons to this model, other than it perhaps is counter to the unstated expectation that the IP role should be filled by an informal volunteer.

We recommend the option of establishing a pool of paid people to act as last resort IPs, and that such a scheme be managed by a community support, community development or advocacy service. The advantages of the latter are that staff in advocacy organisations are already likely to have many of the skills required and familiarity with the IP role, together with the knowledge necessary to carry out this role. Note there is no suggestion staff paid to be last resort IP would be advocates (see later section). We also recommend that in the first instance a pilot be developed and evaluated to refine the criteria for access and how such a last resort IP scheme might work.

Suggestions for Action to Address the Challenging and Potentially Unrealistic Task of IPs

A related issue associated with the design of the IP role and the characteristics of the people whom it supports is the impact that severe intellectual disability has on comprehension and communication. Explaining the proposed use of RRPs—the circumstances under which they will be used, and the reasoning behind using them—so the person understands may be an unrealistic task and is at best complex and challenging.

Current policy and a rights perspective has shifted thinking from a deficit to a strengths approach (Caiels, et al., 2021). This entails identifying and building on strengths rather than dwelling on weaknesses, recognising that everyone has the right to communicate, and the task for supporters is to identify how best to support a person to comprehend the world around them and express their preferences. However, this paradigm shift does not change the reality that people with more severe intellectual disabilities do not communicate symbolically or comprehend the abstract ideas about time, or cause and effect likely to be included in BSPs, no matter how far they are translated into easy read or pictures (Iacono et al., 2009).

Many people with severe intellectual disabilities only communicate preferences through their behaviour, by reacting to people or things in their environment or through movement and facial expression recognisable to others who know them well. It is this group, with more severe intellectual disabilities, for whom participants in the present study suggested the explanatory task of the IP was unrealistic as it was not possible to explain to them the proposed use of RPPs and gain their perspectives.

The qualitative nature of the present study and absence of data from the VSP about those subject to RRPs makes it impossible to estimate the proportion of people subject to RRPs who have more severe intellectual disabilities. However, an unpublished project conducted by OPA about the role of the IP throws some light on this. The OPA study also highlighted the difficult task confronting IPs in explaining the use of RRPs to a person, finding that experienced advocates from OPA were unable to successfully engage with 19 of the 25 people who required an IP about the proposed use of RRPs.

The IP role hinges on explaining and advising and it is not at all clear how an IP should proceed if the person does not understand the proposed use of RRPs, or their rights to appeal, if all the authorisation procedures are followed. (The IP must report non-compliance with procedures to VSP and may do so to VCAT or seek advice from VSP). There are few indications about what an IP should do if the person does not understand the RRPs and the IP is concerned about what is being proposed in a BSP.

The IP role does not extend to advocacy and IPs are not expected to represent the person's interests or support them to pursue their preferences or ensure their rights are met. However, the need for advocacy may arise in situations such as that mentioned above where, for example, a person does not understand the proposed use of RRPs but the IP considers the plan has not fully explored all the possible options or does not reflect good behaviour support practice, or thinks the person needs assistance to make an appeal beyond what an APO offers them.

There is only a fine line between the role of the IP and that of an advocate. The difference was certainly not clear to the three members of the lived experience advisory group who interpreted the IP as playing an advocacy role to ensure their preferences were heard and they were included in decision making about their lives. From their perspective the IP role was a more active one that involved supporting them to have their rights respected.

One way of resolving this issue is to provide greater clarity about the IP role to avoid confusion between the role and acting as an advocate for the person. This would require information for all

those involved, including the people subject to RRPs about the IP role and differences between it and advocacy, and guidance to IPs about securing an advocate for the person if they think for any reason their rights are not being strongly upheld.

A more far-reaching alternative would be incorporating advocacy into the IP role. This would require significant change to the role and perhaps undermine its original intent. It may also confound the need for advocacy and wider system change voiced by the lived experience advisory group with the specific and narrow role of the IP.

We recommend clarifying the differences between the IP role and advocacy and ensuring good information for everyone involved in the IP role about identifying the need for advocacy and how to secure advocacy for a person if necessary.

Suggestions for Action to Achieve Greater Specificity of the IP Role

A further reason why the IP was not working as intended was that some IPs did not have the type of relationship with the person, or the knowledge and skills required to carry out the IP role effectively. There are no minimum requirements or criteria for IPs other than not being a provider of services to the person. The absence of criteria extends to explicit expectations about IP's understanding of the role, type and longevity of their relationship with the person and the suitability for the role.

Study participants explained at some length what they saw as the pre-requisites of suitability for the IP role. These are captured in the findings section and included having a relationship with and knowing the person they are involved with as well as more general knowledge and skills in communicating with people subject to RRPs such as understanding about the impact of earlier life experiences and of having an intellectual disability. Participants also thought it was important to have an understanding of the disability regulatory and service systems, BSPs, RRPs and behaviour support practice. Knowledge about behaviour support—such as what BSPs should include, how to read them, and the types of options that should be considered before the use of RRPs—was seen as increasingly important given the perceived diminishing resources available to practitioners for BSP preparation, the falling quality of plans, and the variable skills of behaviour support practitioners.

We recommend clarifying and strengthening expectations about the way the IP role is fulfilled and suitability for the role. There should be expectations that IPs understand the IP role and have participated in some form of training that includes knowledge about rights of people with disabilities, the role of the IP, rationales for and alternatives to the use of restrictive practices, behaviour support practice, and processes for development of behaviour support plans. Training may also extend to the reasons why people use behaviours of concern, good everyday support practice, and communication skills.

We recommend that expectations about the type of relationship between IP and the person they support are explicit. There should be an expectation that IPs are in regular contact, at least monthly with the person they support, and have a good knowledge about their current situation, interests, preferences and ideally their life history. IPs should not have conflicting interests and thus should not be providing paid services to the person, although 'last resort' IPs may have a paid rather than informal relationship with the person.

There should be an expectation that the IP role is an ongoing role, so there is continuity over time, and they have a long-term perspective about the use of restrictive practices as part of a person's behaviour support plans.

Suggestion for Action to Increase Capacity of IPs and Support for their Role

Insufficient resources dedicated to supporting the IP role is a final reason that the IP role does not work as well as intended. The findings suggested there is no active oversight of the way the IP role is fulfilled, or monitoring of who is appointed to the role such as their relationship to the person, or length of appointment. Our findings also indicated that some IPs were uncertain about the role, and there were no proactive mechanisms to equip IPs for the role. The only resources available to IPs were a somewhat dated Toolkit and opportunity to seek guidance from VSP practice advisers. The extent that these resources were used was not clear, although data from the VSP suggested calls from IPs made up only a very small part of their advice work.

We recommend a stronger IP oversight role for the VSP. At a minimum some form of monitoring by the VSP would ensure data were available about the IP role; how it is carried out and by whom. Data of this nature could be collected directly from IPs when they are appointed and through an annual survey about the types of work they have done in the IP role. This could be used as part of a continuous improvement process that shares knowledge about the role among IPs, demonstrates the value the role adds to safeguarding systems, and ensure IPs meet the minimum criteria for the role. Some form of monitoring may also help to bring greater gravitas and importance to the IP role.

We recommend a stronger IP role for the VSP and development of a suite of strategies to train and support IPs. Strategies should include redevelopment of accessible high quality contemporary training materials for IPs about their role and include knowledge (as described above) about rights of people with disabilities, rationales for and alternatives to the use of restrictive practices, behaviour support practice and processes for development of BSPs, reasons why people use behaviours of concern, good everyday support practice, and communication skills. Face to face or synchronous online training sessions should regularly be offered to IPs as well as a monthly community of practice, drop-in advice sessions and a telephone advice service. A dedicated role in the VSP should be created to curate, update and promote training resources and sources of advice for IPs.

We understand that resources are currently being developed for APOs which are likely to include information to support them in their role in respect of IPs. It will be important to ensure that information and resources provided to APOs about their roles via IPs aligns with that provided to IPs about the role of APOs.

Suggestions about Influencing the Broader Regulatory and Behaviour Support System

The nature and operations of the national system for regulating RRPs and standards for behaviour support practice setting are integral to the quality of Victorian regulatory practices. Throughout our data, attention was drawn to problems at the national level that were impacting on the quality of practice and behaviour support for people in Victorian services. This included for example, concerns about the diminishing resources available in terms of time for the preparation of BSPs, the length and complexity of plans, failure of some practitioners to adhere to practice standards that require the person to be consulted as part of the process, and low accreditation standards for behaviour support practitioners. These issues are not new, are well known by the VSP, and are being tackled through a process of national law and policy reform. We strongly encourage the VSP to continue to influence a national agenda of improving the quality of behaviour support practice through better training and accreditation for behaviour support practitioners.

We recommend the VSP continue its efforts at a national and state level to positively influence the quality of BSPs and behaviour support practitioners and ensure all plans involve the person in the development process as required by the NDIS rules.

Mechanisms could be proposed for greater monitoring of this requirement such as reporting the steps taken by the practitioner to include the person themselves in the assessment process as well recording the practitioner's perspective about the person's understanding of the proposed use of restrictive practices, and the person's views and those of the IP about the use of restrictive practices.

Action to Address the Social Isolation of People Subject to RRPs.

We noted earlier ongoing concerns about the social isolation of people with intellectual disabilities which negatively impacts on people's quality of life as well as the availability of IPs. The body of evidence about initiatives to tackle social isolation is now substantial but few programs have this as their primary purpose. NDIS funding for individuals is often only sufficient to purchase support from relatively unskilled support workers, who are only equipped to act as paid companions in the community rather than act as community connectors. The VSP could play an important leadership role in tackling this issue through developing a demonstration program that aims to develop and support longer term informal relationships between people with intellectual disabilities and community members.

We recommend the VSP invest in a demonstration program, through an NGO to build and support the development and maintenance of long-term informal relationships between people with intellectual disabilities and community members.

The program would be targeted for people who do not have strong family connections or community networks. This type of initiative would reduce the number of people reliant on the last resort service, recommended above, and may in the longer term obviate the need for such a service. The demonstration program should be designed from the existing body of evidence about community connection programs for people with intellectual disabilities. A demonstration program of this nature to build community networks aligns well with the recommendations of the Disability Royal Commission and should be seen as a separate initiative to the IP role and a long-term change initiative that would have benefits in ensuring people have others in their lives who can play the role of IP.

Summary of Recommendations

- We recommend the option of establishing a pool of paid people to act as last resort IPs.
- We recommend clarifying the differences between the IP role and advocacy.
- We recommend clarifying and strengthening expectations about the way the IP role is fulfilled and suitability for the role.
- We recommend that expectations about the type of relationship between IP and the person they support are explicit.
- We recommend a stronger IP oversight role for the VSP.
- We recommend a stronger IP role for the VSP and development of a suite of strategies to train and support IPs.
- We recommend the VSP continue its efforts at a national and state level to positively influence the quality of BSPs and behaviour support practitioners and ensure all plans involve the person in the development process as required by the NDIS rules.
- We recommend the VSP invest in a demonstration program through an NGO to build and support the development and maintenance of long-term informal relationships between people with intellectual disabilities and community members.

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