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Department of Health and Aged Care

Monitoring & Evaluation of the Primary Care Enhancement Program Pilot:

Executive Summary of the Final Report

Submission Date: 2 July 2024

Submitted to:

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Acknowledgement

Abt Associates acknowledges the Jagera and Turrbal people as the Traditional Owners of the land upon which the organisation's Brisbane office is located and the Ngunnawal people upon which our Canberra office is located.

We acknowledge the Traditional Owners of lands across Australia where we conduct our work and pay our respects to, and recognise Elders, past, present and future for they are the custodians of the memories, the traditions, the cultures and the hopes of Aboriginal and Torres Strait Islander Australians.

We recognise the individuals and organisations we have worked with, and will continue to work with, in developing our Reconciliation Action Plan (RAP).

Our Vision for Reconciliation

Our vision for the future of Australia, is one where our nation is actively anti-racist, promotes equality and equity, one that celebrates diversity and embraces unity between Aboriginal and Torres Strait Islander peoples and the broader Australian community.

Our organisational mission is to strengthen the communities in which we work, by improving the social and economic wellbeing of all. Guided by the United Nations Declaration on the Rights of Indigenous Peoples, which sets out the minimum standards for the continued survival of, and level of respect and wellbeing for all Indigenous peoples, we aim to be an active participant in the reconciliation journey that Australia continues on, as well as a role model for other mission-driven organisations.



Our RAP artwork, by Stephen Hogarth a descendent from Gamilaroi is an important visual depiction and symbol of Abt's RAP story and journey.



Abbreviations and acronyms

Abbreviation	Full text	
Abt	Abt Associates	
CCQ	Country to Coast Queensland	
CDP	Curriculum Development Project	
CESPHN	Central and Eastern Sydney Primary Health Network	
CID	Council for Intellectual Disability	
CQWBSCPHN	Central Queensland, Wide Bay, Sunshine Coast Primary Health Network	
DoHAC	Department of Health and Aged Care (also, the Department)	
GP	General Practitioner	
MBS	Medicare Benefit Scheme	
NDIA	National Disability Insurance Agency	
NDS	National Disability Services	
NCE	National Centre of Excellence in Intellectual Disability Health	
RACGP	Royal Australian College of General Practitioners	
SIL(S)	Supported Independent Living (Service)	
PCEP	Primary Care Enhancement Program	
PHN	Primary Health Network	
PHT	Primary Health Tasmania	
QI	Quality Improvement	
WVPHN	Western Victoria Primary Health Network	



Key terms and definitions

The following definitions have been applied throughout this report. Abt recognise that perspectives may vary regarding the acceptability of specific terminology.

Term	Relevant definition used within this report	
Client	A person or group receiving a service, including disability support, peer support	
Consumer	A person who has used or may use a healthcare service, or a consumer representative or advocate Source: Australian Commission on Safety and Quality in Health Care	
Patient	A person or group receiving healthcare services Source: Australian Commission on Safety and Quality in Health Care	
Sector mapping	A process of identifying and analysing a range of services, supports, stakeholders, networks, partnerships, programs and initiatives and how they relate to each other. This includes identifying roles and responsibilities, and interdependencies. For the purpose of this report, sector mapping includes health and disability services relevant to the health and wellbeing of people with intellectual disability.	



1. Introduction

Abt Associates were engaged by the Department of Health and Aged Care (the Department) to monitor and evaluate the <u>Primary Care Enhancement Program</u> (PCEP) pilot between July 2022 and June 2024. The PCEP is an initiative under the <u>National Roadmap for Improving the Health of People with Intellectual Disability</u> (the Roadmap) and aims to:

- increase the skills and ability of GPs and other health professionals to deliver effective health care for people with intellectual disability
- improve the health literacy of people with intellectual disability.

2. PCEP Implementation

The PCEP pilot is being delivered by four Primary Health Networks (PHNs): Central and Eastern Sydney PHN (CESPHN); Western Victoria PHN (WVPHN); Primary Health Tasmania (PHT); and Country to Coast Queensland (CCQ) - formerly Central Queensland, Wide Bay and Sunshine Coast PHN.

Four implementation 'work streams' were agreed with pilot PHNs during evaluation co-design, including:

- Workforce training and development the design and delivery of training and support for primary care professionals, including GPs, allied health professionals and other relevant primary care staff.
- Care pathways the development and promotion of HealthPathways an online clinical information portal, integration of the PCEP across other PHN programs, and service navigation support.
- Information and resources the development, adaptation and distribution of the PCEP resources, including promotion of annual health assessments.
- Engagement and advocacy the establishment and operation of local PCEP advisory groups, and building of stakeholder networks that support the PCEP implementation and monitoring objectives.

All PCEP project teams had formed by the end of 2021, and the suite of PCEP training and health literacy resources developed by the Council of Intellectual Disability (CID) were available to PHNs by end of March 2022. Local needs assessments were undertaken by all PHNs to inform program design. All sites continue to integrate feedback into their program design, and CCQ and PHT (as of January 2024) are undertaking further care pathway mapping and program redesign. All PHNs developed a partnership with one or more local co-facilitators with intellectual disability to design and deliver training, however, this varied in frequency and approach across PHNs. Importantly, the ongoing impacts of the COVID-19 pandemic led to delays in implementation of the PCEP as PHNs were tasked with COVID-19 related activities, and/or reduced opportunities to engage externally.

Early in the pilot, training, engagement and the PCEP resources were expanded to be relevant for all primary care staff, such as practice managers and reception staff. Over time, PHNs also identified opportunities for enhancing skills of other roles that can influence the care experience of people with intellectual disability. This led to further expansion of training, resources and support to target disability



support workers, families and other support persons. The PHNs will continue to implement the PCEP pilot until end June 2024.

3. Evaluation Methodology

The monitoring and evaluation of the PCEP pilot includes the following key evaluation questions (KEQ):

- 1. How effective has the PCEP been at improving knowledge, attitudes and skills of primary care providers in providing health care to people with intellectual disability?
- 2. How effective has the PCEP been at improving access to resources about health care for people with intellectual disability?
- 3. What are the key factors to consider if the PCEP was to be rolled out nationally?

The evaluation was guided by a co-design process and a detailed evaluation plan that was approved by the Department and Bellberry Human Research Ethics Committee. Data collected included:

- bi-annual program implementation reports from each PHN
- 472 pre-, 351 post- and 82 follow-up external training surveys
- 111 PHN staff surveys
- consultation with 248 stakeholders, including 36 people with intellectual disability.

Other PCEP stakeholders participating in consultations include support persons, trained providers, PHN staff, co-design and co-facilitation representatives, disability support organisations, peak bodies, and local advocacy organisations. A community of practice for PCEP teams was also established to share information and learnings across pilot sites. Abt met with the Department's PCEP project team and reported on issues and findings regularly through the evaluation.

4. Evaluation Findings

KEQ 1: HOW EFFECTIVE HAS THE PCEP BEEN AT IMPROVING KNOWLEDGE, ATTITUDES AND SKILLS OF PRIMARY CARE PROVIDERS IN PROVIDING HEALTH CARE TO PEOPLE WITH INTELLECTUAL DISABILITY?

The PCEP pilot has led to improved knowledge, confidence and practices among training attendees. Key survey findings¹ for training attendees include:

- The proportion of respondents indicating knowledge of inclusive communication strategies increased from 40 percent before training to 92 percent after PCEP training.
- Respondents' confidence in supporting annual health assessments for people with intellectual disability increased from 34 percent pre-training to 72 per cent after PCEP training.

 $^{^{\}rm 1}$ Refer to section 6 of full report for further detail on the inclusions and exclusions of the survey data.



• Eighty-four per cent of respondents to the follow-up training survey (collected 3-12 months after training) reported they apply their PCEP learning into reasonable adjustment practices for people with intellectual disability always or most of the time.

General practitioners (GP) were a primary target group of the PCEP; however, findings indicate that there was low engagement by GPs in the initial stages of PCEP implementation. Identified reasons (by PHN staff and providers) for low engagement include very few patients with intellectual disability, competing priorities, and lack of understanding of practical opportunities to better support patients with intellectual disability. As awareness of the PCEP has grown, and PHNs have a better understanding of practices' education needs and topic preferences, there is growing evidence of more interest and engagement in the PCEP. Whilst the training is effective in enhancing knowledge and confidence, it has not reached the GP target audience as expected. PHNs expanded the training to include other practice staff such as reception and practice managers, and this has increased opportunities for impact.

Identified areas of improved knowledge, confidence and practices among primary care providers include:

Topic	Changes in knowledge/confidence	Changes in practice
Communication	 talk to patient (not their support person) use more visuals ask questions, avoid assumptions advocating for patient's rights 	 seek /add patient preferences to notes send appointment reminder texts use images in shared information
Adjustments to meet the needs of people with intellectual disability	 provide options for scheduling longer / additional appointments 	 book appointments at quiet times book longer appointments stagger patients with intellectual disability across week
Local services	 availability of local services and supports, access to PCEP team HealthPathways specific to PCEP 	 connect with patient's disability support organisation / coordinator
Understanding the needs of GPs and practices	 team-based approaches to optimising provider's time with patients – including the CHAP 	 optimise roles for CHAP appointments increase time for planning ahead collaboration - allied health, GP

Promotion of HealthPathways through the pilot increased awareness among providers engaged in the PCEP of using it as a tool to support enhanced care for people with intellectual disability. Due to limited evaluation feedback from HealthPathways users and limitations of data analytics, the impact of the PCEP on use of HealthPathways is not known. HealthPathways is identified as a key tool that can support



promotion of the Comprehensive Health Assessment Program (CHAP) and access to important local service and referral information.

There is also emerging evidence that primary care practices receiving tailored PCEP support have increased understanding of the importance of identifying patients with intellectual disability. This will be monitored as more data is available. Further changes in practice are expected as further data is collected, acknowledging the evidence that improved knowledge and confidence leads to improved practices in primary care. Further and more sustainable changes in practice are also expected as PHNs implement tailored education approaches.

Stronger networks as a driver to enhanced care

The pilot PHNs have built local networks of health and disability stakeholders over time. This has raised awareness of the PCEP, built PHN and provider knowledge of local services, and led to some examples of improved care coordination. Stronger service and professional networks appear to be a key driver of changes in practice. Engagement with external networks has also enabled PCEP teams to gain a local reputation as a key intellectual disability health support role for resources and service navigation.

Disability inclusion as core business for PHNs

The PCEP teams have also prioritised embedding disability inclusion across the PHN. Consultations and surveys of PHN staff show the PCEP has benefited broader PHN staff and programs, with outcomes including:

- improved awareness among staff of the PCEP and the PHNs role in disability inclusion
- a disability inclusion action plan (CESPHN) and diversity and inclusion policy (WVPHN)
- discussions about integrating disability inclusion across commissioned services.

This was supported by findings of the PHN staff survey, where 80 per cent of respondents (75 of 93) agreed their PHN has a **key role in supporting intellectual disability inclusion in its core business**.

KEQ 2: HOW EFFECTIVE HAS THE PCEP BEEN AT IMPROVING ACCESS TO RESOURCES ABOUT HEALTH CARE FOR PEOPLE WITH INTELLECTUAL DISABILITY?

The PCEP has **improved** *awareness* of where to find intellectual disability health resources, including access through the PCEP team. PCEP teams also developed practical tools, informed by local stakeholder feedback, such as the patient profile template and MBS item information sheets increasing the overall suite of resources for primary care providers. Survey findings suggest that training increased knowledge and confidence of where to find key information. This, along with having helpful and relevant resources, is expected to lead to improved resource use in practice over time. The most useful resources for providers include the CHAP tool promoted through the PCEP; and the patient profile template, MBS item information and a list of available local services for referrals all developed specifically for the PCEP.

A small number of training attendees and other stakeholders interviewed identified that the PCEP has led to increased *access* to and *use* of intellectual disability health resources over time. Other training attendees interviewed, identified their access to and use of resources had not changed since the training, with reasons cited as limited time and capacity or not having the need to review the shared resources.



People with intellectual disability identified the health promotion fact sheets and patient profile template developed as part of the PCEP as helpful discussion tools for using in an appointment with the health care provider. The patient profile was considered beneficial as it provides a record of preferences and information that avoids retelling their story to a provider at each appointment. There was limited distribution of resources directly to people with intellectual disability by PCEP teams, who primarily relied on trained providers and other PCEP engaged stakeholders to share the resources with their patients, communities and networks.

PCEP teams invested significant effort into developing and adapting resources to meet local stakeholders' needs including: recorded webinars, instructional videos, PCEP web pages, and a learning management system. More than 240 new resources were developed or identified as an existing resource to supplement the suite of CID resources. These resources will be important for curating a suite of materials for the PCEP in the future. Stakeholders identified a preference for accessing resources from a central location in any future PCEP initiatives.

KEQ 3: WHAT ARE THE KEY FACTORS TO CONSIDER IF THE PCEP WAS TO BE ROLLED OUT NATIONALLY?

Key insights to consider if the PCEP was to be rolled out nationally are provided below.

Continued monitoring and evaluation across the pilot sites for a further 12 months is likely to build on current evidence of effectiveness

PHNs required extensive time to build the PCEP pilots that address local stakeholder needs and preferences, and build awareness and networks among external stakeholders. This limited the potential for collecting evaluation evidence for changes in practices among primary care providers. Evidence is also limited due to low engagement by GPs and general practice more broadly, and the time and planning required to embed learnings into practice. In March 2023, the PCEP was still considered to be 'in its infancy', representing an opportunity to continue to build on the momentum through 2023 and 2024. Literature also suggests that improved knowledge and confidence will lead to improved practices among primary care providers². Further evidence of improved practices is expected to be demonstrated in the future, and this should be a key factor in considering if the PCEP is rolled out nationally.

2. Comprehensive PCEP national guidance for local implementation informed by pilot learnings will enable a more effective and sustainable PCEP

Access to a more detailed program guidance document for PHNs would benefit PHNs in the future to deliver a more effective and sustainable PCEP. This could be informed by the pilot key learnings, with further learnings considered as they are available as part of a regular guidance review process. Guidance should provide good practices for local sector mapping and analysis, needs assessment, stakeholder engagement, workforce, implementation and promotion. Key components for an effective and sustainable PCEP include the following:

 $^{^2\} https://qualitysafety.bmj.com/content/28/7/582; https://www.ahrq.gov/research/findings/factsheets/quality/qipc/index.html$



- Local sector mapping and analysis should be comprehensive and include relevant stakeholders, services, networks, programs and initiatives and their relationships see also key insight 4. This can provide a contextual baseline for PHNs and enable contextualised local program design.
- The PCEP to be guided by a comprehensive local external engagement and communication plan
 that details roles and responsibilities across all PCEP stakeholders. This should align with roles and
 responsibilities of PCEP stakeholders at a national level (to be led by the Department). This can
 guide the most appropriate approach for engagement that aligns with stakeholder capacity and
 capability.
- Local delivery of training and support to be guided by national approach, and local co-design. This
 can reduce duplication of efforts and enable consistent messaging which can enhance fidelity to
 the program's objectives. Local delivery enables convenient access to locally relevant service
 information.
- PCEP team to be a dedicated and experienced team that is ready to lead and advocate at the
 outset, and supported by the PHN Executive and other relevant internal teams. This can ensure
 the team has the management and problem-solving skills and capacity required to deliver a
 successful program.
- Collaborate with internal PHN programs to promote the PCEP, leverage networks and support
 priority areas including Aboriginal and Torres Strait Islander health, health of culturally and
 linguistically diverse communities, aged care, domestic and family violence, dementia, mental
 health. This can improve intellectual disability health awareness among providers caring for
 priority populations.
- Prioritise disability inclusion strategically in the PHN, including through internal awareness raising, ongoing impact monitoring, reciprocal cross-program promotion, consideration of commissioning cycle opportunities, and exploring potential for disability inclusion practice liaison role. This can increase awareness among their local external stakeholders of its importance and relevant practical steps. This would demonstrate the Department's commitment to disability inclusion, and to understand readiness among external stakeholders.
- Establish a local advisory group that is diverse with strong networks to enhance reach and impact.
 This can enable a role for local champions who promote PCEP and increase broader buy-in, and leverage broader local networks to increase program effectiveness.
- Integrate local lived experience role/s and approach, to be determined by the PHN for example
 consider role/s in co-design, advisory group, and co-facilitation of local training and support.
 Stronger messaging from people with lived experience can increase likelihood of information
 retention.
- Partner and collaborate with local organisations that have strong links with local communities. For example, disability advocacy organisations, multicultural community groups, or intersectionality advocates. Collaboration could include attendance at community events, or partnerships with local community and advocacy organisations to lead the PCEP engagement with local consumers. This can optimise awareness of the program among consumers and local community, and enhance opportunities for distribution of PCEP resources.



- Consider other locally feasible options for enhancing access to resources for people with
 intellectual disability and support persons. This may include a 'peer support worker' model, to
 extend the capabilities and reach of the PCEP team to rural health services, patients, communities.
 This can enable meaningful co-design and innovative approaches that can improve effectiveness.
- 3. Establishment and maintenance of a national intellectual disability health resource hub will support consistent messaging, reduce duplication and enhance reach

PHNs have developed and adapted an extensive range of PCEP training and health promotion resources that have supplemented the resources produced by CID and are nationally relevant. The PCEP would benefit from a nationally consistent set of resources, accessible centrally, supplemented by local service information. This resource hub would reduce duplication and align key messaging. PCEP resources, where relevant, should build on existing material identified through the PCEP, the Curriculum Development Project (CDP) and the National Centre of Excellence in Intellectual Disability Health (NCE). Resources should include training materials, tools, and templates and health promotion information. Other key learnings on effective and sustainable PCEP resources and access include the following:

- Each PHN to develop local resources such as HealthPathways and lists of available services and supports, whilst the Department explores access to a core suite of nationally consistent resources.
 This can reduce duplication of common resources being developed across multiple PHNs, and ensure consistent national messaging which is more likely to be sustainable.
- Distribution of PCEP resources to be a key function of the program to enhance awareness, and enable increased health literacy among people with intellectual disability and other stakeholders.
 This can enable people with intellectual disability and their support persons to self-advocate (e.g. CHAP).
- Local / regional resources should be accessible through the PCEP team, PHN webpage and HealthPathways, and in line with the PHN's approach to engaging consumers. This can support efficiency as it builds on existing systems of information sharing.
- National resources to be made available through a centralised access or resource hub. This is convenient, simplifies navigation, ensures consistent messaging and can reduce time required for maintenance.
- Centralised resources to also be available and promoted via usual information channels for each stakeholder group. For example: (i) people with intellectual disability and their supports: via providers, support person, advocacy groups, parent, internet, NDIA; (ii) primary care providers: via practices, and relevant peak bodies for GPs, allied health professionals, nurses, practice managers. This can increase efficiency by simplifying resource navigation, and increase awareness opportunistically.
- 4. A clear and shared understanding of health and disability sectors at a national level will enhance an understanding of sector roles and opportunities / priorities for optimising the delivery of PCEP

Sector mapping and engagement undertaken in the pilot led to the PHNs' enhanced understanding of the local health and disability service interface. It also increased the awareness of external stakeholders, particularly in the disability sector, of the PHNs and their new role in intellectual disability health. The



PCEP would benefit from a national sector mapping process to ensure a consistent understanding by PHNs and PCEP stakeholders, of relevant intellectual disability health services, roles and networks across Australia. Outputs of a national mapping exercise could support the development of national PCEP guidance, local approaches to sector mapping, and strategic partnerships for enhancing person-centred care.

5. Strategic partnerships among key health and disability agencies and peak organisations at a national level will enable opportunities for broadening promotion of the PCEP, and highlight opportunities to address key systemic challenges

PCEP teams have leveraged their external networks to increase the awareness and reach of the PCEP locally. Effectiveness and sustainability would be enhanced with health and disability networks and support for PHNs at a national level. This would enable broader promotion, strategic collaboration and support, and increased awareness and buy-in. Relationships built through the NCE and other Roadmap initiatives may be a foundation to build a focus on enhancing the sustainability of the PCEP. PCEP stakeholders identified potential benefits of working collaboratively at a national level with, for example, National Disability Services (NDS), National Disability Insurance Agency (NDIA), Medicare Benefits Scheme (MBS), Royal Australian College of General Practitioners (RACGP), allied health peak bodies, and Inclusion Australia.

5. Ongoing adaptations to program activities

New and adapted PCEP activities are being implemented as PHNs continue to enhance their understanding of local service needs, and integrate stakeholder feedback. PHNs expect these tailored activities, combined with ongoing support and practical resources, will lead to enhanced outcomes. The effectiveness of other implementation activities to be reported over time include:

- Specific activities and outcomes of intensive whole-of-practice support including updating patient data systems with patient identifiers for intellectual disability PHT, CESPHN, WVPHN
- Learning Management System for primary care providers CCQ
- Case conferencing workshop for primary care providers WVPHN
- Further in-language workshops for support persons of people with intellectual disability CESPHN
- Hospital interface patient journey mapping project PHT.

The evaluation also identified **system and operational challenges** that potentially stifle opportunities for providers to implement enhanced primary care for people with intellectual disability. These challenges should be considered by the Department for longer term sustainability and effectiveness along with the above key factors if the PCEP was to be rolled out nationally, and include:

- limited practice software and data collection capacity to identify patients with intellectual disability, and therefore patients who have or need an annual health assessment
- funding siloes between health and disability and perceptions about divisions of responsibility
- limited primary care incentives for supporting patients with complex needs.



6. Data limitations

The participating PHNs tailored the PCEP pilot to the needs of their regions. With changing needs, the pilot evolved over time, introducing variation in the implementation of the PCEP between the four PHN regions. Five key limitations to data gathering were identified during this evaluation.

- Response from primary care providers: There was lower participation in the interviews and online surveys from general practitioners (GPs), however the response from allied health professionals and general practice staff was satisfactory. The interest and engagement with the PCEP from the community and disability sectors was higher compared to the engagement of the overall primary care providers. As GPs are key primary care service providers, limited engagement of GPs added limitations to the reach of the PCEP and information that could be gathered during the evaluation.
- Inputs from people with intellectual disability: Due to limited support from primary care
 providers into coordinating evaluation feedback from their patients with intellectual disability,
 there was limited direct feedback of impacts of the PCEP on their health experience. Adapting the
 methodology helped to gather this input directly from the people with intellectual disability.
- Survey data gathering process: The proposed initial evaluation methodology was to collect pre-,
 post- and follow-up PCEP training surveys mapped to the CID content. During the PCEP
 implementation, the content changed and resulted in some survey questions being of limited
 relevance in the post- or follow-up surveys. This impacted the data gathering processes over time.
 In addition, most surveys collected were from stakeholders in WVPHN, followed by CESPHN.
- Timeframe of the evaluation: Extensive time and resources were used by PHNs to build
 awareness and interest in the PCEP. Investing time in co-design and stakeholder engagement
 helped build traction, however the potential impact of the pilot was delayed. This resulted in a
 shorter evaluation timeframe to measure impacts of the PCEP, particularly in PHT and CCQ. Thus,
 the evaluation is limited to evaluation of short- and medium-term outcomes of the program logic.
- Attribution of any changes to the PCEP: Quantitatively measuring attribution to the PCEP of the
 observed improvements in health outcomes was not feasible for this evaluation. However,
 qualitative evaluation data sought information on specific impacts of the PCEP training,
 attendance at previous training, and work or lived experience on these improvements. This data
 informed the contribution of the PCEP to any observed improvement.

7. Conclusion

Overall, the PCEP pilot has led to improved knowledge, confidence and skills of the primary care providers and other stakeholders who received training and support from the PHNs. The PCEP also improved awareness of relevant resources shared among the engaged stakeholders. Delayed implementation of the PCEP and the time necessary to establish local program activities in each of the PHN regions, impacted the evaluation timeline and the data available for this evaluation. There were also limitations in evaluation data collection due to low engagement and response rates from primary care providers. Continued monitoring and evaluation would enable further exploration of 1) the ongoing impacts of the PCEP, and 2) program adaptations made locally and that consider the key insights from this evaluation.



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