



# Perspectives in Early Intervention

## Consumer participation in a youth mental health service

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### Abstract

**Aim:** Consumer participation is increasingly being understood in both a policy and a practice context as an essential component of mental health service planning, delivery and evaluation. Existing models of participation benefit from adaptation to suit the early intervention context.

**Methods:** This paper describes a unique programme of 'youth' consumer participation occurring at Orygen Youth Health (OYH) – an early intervention service in Melbourne, Australia. Flexibility and support are key components of the model. As well as supporting increased consumer-centredness of service delivery, the

model aims to support the recovery of those involved in participation activities.

**Results:** The programme described is comprehensive, multimodal, continues to evolve and is successful based on anecdotal feedback. However, there are no evaluation data to support its attainment of outcomes.

**Conclusion:** Consumer participation is an essential part of mental health service development, delivery and evaluation and must be incorporated into early intervention services. As programmes of participation evolve, comprehensive models of evaluation must be developed to acknowledge their outcomes.

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### INTRODUCTION

Current Australian mental health policy sees the active and collaborative engagement of consumers in their treatment as of great importance – as both a human right<sup>1</sup> and as a way to improve health outcomes.<sup>2</sup> In the current policy and practice context, consumer participation can be seen to involve three tiers of participation:

- Planning, provision and evaluation of service at the individual level, in which consumers participate in decisions about their own care;
- Service-wide planning, service provision and evaluation, in which consumers are valued stakeholders and consultants; and
- Structural or systemic planning and evaluation, in which consumers are engaged in consultation regarding new policy development.

These have been categorized as 'individual', 'local' and 'systemic', respectively.<sup>3</sup> Consumer participa-

tion at these levels has the capacity to improve service quality, improve health outcomes for those involved, make services more responsive to consumers' needs and improve health outcomes of the wider population of consumers.<sup>4</sup> Far from being adjunct to core service delivery, consumer participation has been identified as an 'essential' component of early intervention services (EIS).<sup>5</sup>

The most commonly adopted model of consumer participation within the Victorian public mental health system is that of employed consumer consultants.<sup>6</sup> Consultants may run focus groups and support groups, may represent consumer interests on organizational committees and steering parties, and may work as Peer Support workers (PSWs) and consumer advocates. This paper will describe the ways in which this usual model of consumer participation has been adapted for use in an EIS. It will demonstrate how models of participation and representation in EIS benefit from the incorporation of flexibility and support as key components, and how

this supports both meaningful participation and recovery. The importance of evaluation of programmes of consumer participation will be described, and proposed methodology for evaluation will be briefly introduced.

## METHODS AND RESULTS

### Orygen Youth Health (OYH)

OYH is a youth mental health service located in Melbourne, Australia. OYH incorporates a clinical programme (OYH-CP), a research centre (OYH-RC) and a training and communications programme (OYH-TC). The specialist clinical programme works across the north-western and western suburbs of metropolitan Melbourne. The service is composed of a range of specialist outpatient clinics, an inpatient unit, psychosocial recovery programmes, an access team and a family support programme. The objectives of consumer participation at OYH differ from those in purely clinical services. At OYH, the objectives of consumer participation are to

- Improve service delivery to clients of the service;
- Improve mental health literacy and promote help-seeking among young people; and
- Reduce stigma regarding mental illness.

### Service description

Youth participation is overseen by the psychosocial recovery programme. A youth participation coordinator (YPC) is employed (0.6EFT) to liaise with various components of the OYH service and wider system, and to engage young people in participation activities. Past incumbents in this position have had backgrounds in education, youth work and community development. The YPC oversees two consumer-employees (0.4EFT) who are project workers in the core components of OYH's youth participation model, the Platform team and the Peer Support project. The YPC is supported by a youth participation steering committee (steering committee) (see Fig. 1).

#### *The platform team*

The Platform team (Platform) is composed of past and present clients of OYH-CP who are interested in working together to inform service development and delivery. The team meets fortnightly and new members join regularly. Fortnightly meetings provide opportunities for a range of 'top-down' and 'bottom-up' consultations. 'Top-down' consulta-

tions include research projects, service changes, psycho-education materials and a range of other initiatives. Requests to meet with Platform are made to the YPC, who then assists staff to consider how to make their consultation accessible and effective (e.g. reducing the use of jargon, making research processes more easily understandable). An opportunity to consult with Platform is scheduled. Information may be disseminated to members beforehand for their preparation. The staff member meets with Platform and consults regarding the acceptability and appropriateness of the initiative, and seeks Platform's ideas about making the project more acceptable and appropriate. Minutes are taken, and further consultations or email follow-up may occur in order to maximize the young peoples' involvement (see Text Box 1).

In addition to service-driven consultations, Platform members use meetings as opportunities to explore and develop their own ideas about service improvement and service development, particularly in response to findings of an annual service-wide 'Consumer Experience of Care' survey. In these conversations, the YPC supports the team to develop ideas and to consider steps for further action. Working parties may emerge and individual members may go away with actions to undertake before the next meeting. The YPC may invite relevant members of the steering committee to subsequent Platform meetings to support the development of a Platform initiative.

As well as attending Platform meetings, Platform members may engage in a range of other activities (see Fig. 2). This 'menu' of activities has developed over time, in response to both professional and consumer stakeholders. Prospective participants register their interest in these activities with the YPC, who ensures that they receive adequate training and are added to the register of individuals who are interested and trained in this kind of participation (see Fig. 2; see also Table 1). When OYH staff or programme areas wish to adopt or engage with different elements of participation (e.g. on an interview panel, in a training presentation), a request is made to the YPC, and the YPC coordinates and supports the involvement of young people.

#### *The Peer Support programme*

One of the 'bottom-up' initiatives emerging from Platform has been the Peer Support programme. This programme aims to instil hope in young people experiencing mental illness; support clients to actively engage with the recovery process; reduce the trauma, disorientation, and boredom associated

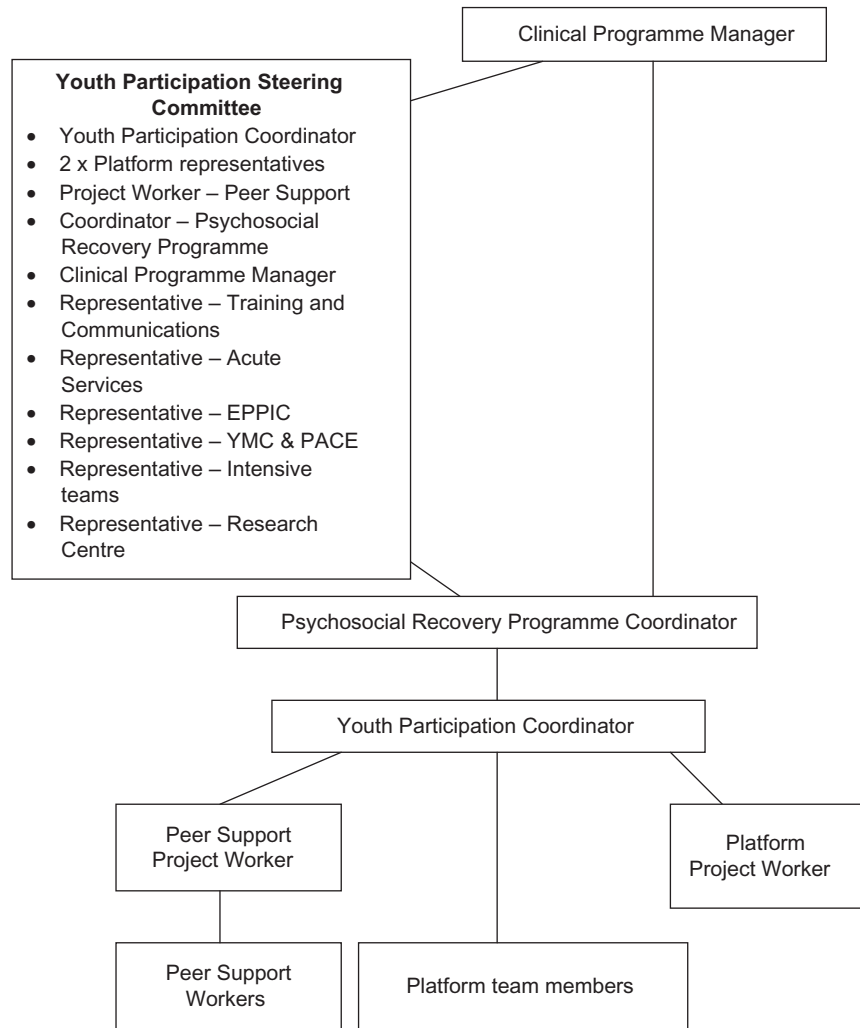


FIGURE 1. Governance structure for youth participation at Orygen Youth Health.

with hospital admission; and provide peer-delivered psycho-education. PSWs are recruited from interested ex-clients of OYH-CP and are engaged in a comprehensive training package. Following training, PSWs volunteer their time via a roster system to go to the OYH inpatient unit or to operate a drop-in room co-located with outpatient services.

On the inpatient unit, PSWs work with hospitalized young people to support engagement in meaningful activity and peer interaction. PSWs use planned self-disclosure regarding their own illness and recovery to support young people to consider the issues involved in their recovery. At the outpatient site, a drop-in room designed and decorated by Platform and PSWs contains written resources such as psycho-education fact sheets and information on other services available, Internet access, condoms and fresh fruit. PSWs staff the drop-in room and provide opportunities for clients to talk with them about their own recovery experience and think

about how to make best use of their time in the service to support their recovery. PSWs may also take on an advocacy role, supporting clients to understand avenues for feedback and participation (see Text Box 2; see also Table 2).

*The youth participation steering committee*

The steering committee consists of representatives from all OYH programmes, the YPC and young people. As well as ‘steering’ the continued development of youth participation, steering committee representatives ‘champion’ youth participation in their programme areas, aiming to embed participatory and consultative practices within their teams.

Not all programmes engage with all activities of Platform. There has been a deliberate decision from senior management to not fix consultation and participation requirements in policy, in acknowledgement that it may lead to tokenism,<sup>7</sup> or may result in

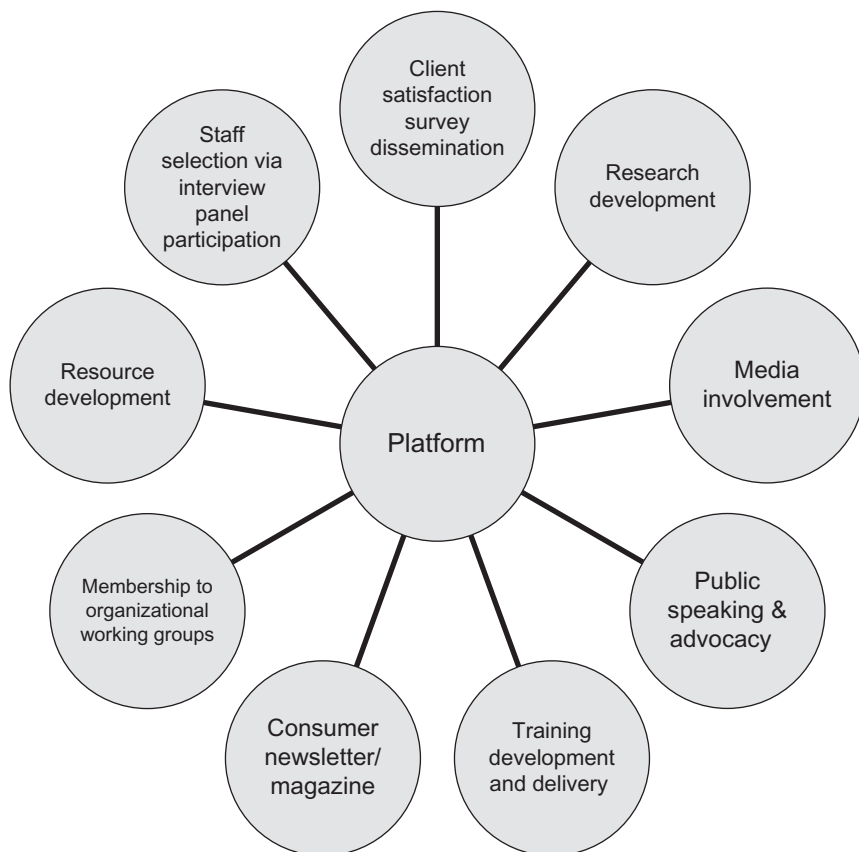


FIGURE 2. Activities Platform members may become involved in.

TABLE 1. Involvement in Platform activities, January–December 2010

Item	Number
Platform meetings	22
Organizational working group meetings	12
Research consultation	6
Media activities	4
Public speaking and advocacy	12
Training development and delivery	5
Staff selection	0
Consumer newsletter	0
Resource development	4
Service development	4
Total number participation activities	69
Total number participating young people	31
Average (mean) number of activities involved in, per participating young person	8

TABLE 2. Peer Support activities, January–December 2010

Item	Number
Peer Support workers	8
New trainees	4
Inpatient shifts (per week)	3
Drop-in room shifts (per week)	2

young people being asked to participate in ways that do not match with their hopes from participation.<sup>8</sup> Instead, the steering committee works to support the increased adoption of different kinds of participation across programme areas by reviewing and responding to barriers and enablers, and championing increased participation.

**Processes and supports**

In order to support meaningful youth participation, as an acknowledgement of the skills young people bring to their roles, their developmental stage and their recovery plans, a number of processes have been introduced to the programme over time. These processes have also worked to allay the concerns of clinical staff who seek clarity around the role of participation in mental health services,<sup>9</sup> worry that youth participation is unnecessarily burdensome for consumers<sup>10</sup> or that it creates ‘professional’ consumers.<sup>11</sup>

When young people first express interest in becoming involved in youth participation activities, they meet with the YPC to discuss the range of ways to become involved. A participation goals form is

**TEXT BOX 1. Staff and Platformer's experiences of consultation.**

Staff:

'Platformers' involvement . . . has been invaluable in helping us get a clear picture of what information young people need rather than just providing what we think they need. Feedback from their personal experiences has allowed us to develop youth mental health resources that are not only theory-driven and useful, but also practical and relevant for young people who are experiencing mental health problems. Their input has been particularly useful as they have a true understanding of the needs of the young people we are trying to reach'.

Young people:

'Having the opportunity to . . . use my experience to improve services and help other young people is really important to me . . . makes me feel empowered'.

'Being able to participate and consult on research projects makes me feel valued and respected for my experience and input'.

**TEXT BOX 2. Peer Support worker and client experiences of Peer Support intervention.**

Peer Support workers:

'I feel very fulfilled when I leave my shift at the Inpatient Unit. I feel like I have made a difference by providing support to those who are going through a very difficult time in their lives'.

'By helping others get back onto their feet, you feel you have a purpose to be proud of. Sharing your experience to help others is just so rewarding'.

Peer Supported young people:

'Peer Support Workers make me feel hopeful – if they can get better, then I can too'.

'Meeting a Peer Support Worker showed me that I can, and will, get through this'.

'Being able to talk to a Peer Support Worker makes me feel connected to someone on my level, who knows what I'm going through'.

**TEXT BOX 3. Requirements for Peer Support workers.**

- Willingness and ability to participate in the programme for no financial gain;
- Willingness and ability to attend to rostered commitments;
- Willingness and ability to be a 'recovery role model' for current clients;
- Willingness to adhere to confidentiality requirements;
- Willingness and ability to attend monthly supervision.

used to identify their areas of interest. This supports the YPC to ensure access to training and to support the young person to become involved in their specific interests.

Before becoming a PSW, young people have an interview with the YPC, the Peer Support project worker and a clinician. This interview provides the prospective PSW with an opportunity to describe their interest in the programme and the skills they bring to the programme, ask further questions about the Peer Support programme, and to consider their willingness to comply with the programme's requirements (see Text Box 3).

All young people participating in Platform or Peer Support complete a wellness plan in collaboration with the YPC. The wellness plan invites the young

person to identify their known coping strategies and supports, as well as any factors that they identify as warning signs of changes to wellness. The wellness plan is introduced to young people as a method to support them to manage any potential stressors of being involved in participation activities and a way to ensure that their wellness is neither jeopardized by, nor jeopardizes, the roles that they may take on during their involvement. Participants are asked to agree to a preferred course of action in the event that the YPC becomes concerned for their wellness. To support recovery and to minimize the burden of the role, PSWs are asked to take a 3-month break from their role after an inpatient admission. (This also supports maintenance of role-boundaries where participants may have been re-admitted alongside

current consumers of the service.) In contrast, involvement in Platform has no wellness requirement and young people can become involved during any stage of their involvement with outpatient programmes at OYH-CP. If a participant becomes more acutely unwell, they may be encouraged to consider reducing their level of involvement. These negotiations occur directly between the young person and the YPC. Although young people may be encouraged to discuss the nature of their involvement with their treating team, their families and others in their life, this is not compulsory.

In acknowledgement that young people's lives change rapidly, the participation goals and wellness plan are reviewed and updated every 6 months or earlier upon the request of the young person. Reviewing participation goals encourages the participant and the YPC to consider personal and professional development opportunities, and once a young person has accessed internal training, that young person will consider external training which might promote progress towards these goals. This process has supported a number of participants to directly use skills acquired in Platform and Peer Support in their further education and training, and in employment. Some Platformers have progressed from participation into avenues such as advocacy organisations and project work. A number of PSWs have continued on to professional and paraprofessional roles, including mental health nursing, social work, youth work and personal care attendant roles.

Alongside the participation goals, wellness plan and training modules sits the PSW group supervision. PSWs attend monthly group supervision with clinical staff, which provides opportunities to develop skills, reflect on their practice, further develop the programme and access debriefing. For more urgent debriefing, PSWs have access to clinical staff and to the formal debriefing channels of the organization.

All young people who participate in youth participation activities are reimbursed as compensation for their time, travel and potential lost income and in recognition of their skills. The YPC keeps a record of activities undertaken by each involved young person not only to primarily ensure adequate payment but also to check against individuals' hopes for their participation to ensure that the programme is assisting achievement of their goals.

The YPC position was originally managed outside the clinical programme in OYH-TC, with the intention of using the role of pseudo-outsider to advocate for increased participation.<sup>12</sup> As organizational culture has evolved and participation activities have

been increasingly adopted, the position has been moved into the clinical programme. This has enabled ease of communication between participating consumers and the wider clinical programme. It also increases the visibility of activities and outcomes of the youth participation programme, responding to recent research which suggests that increased exposure to local-level participation activities increases the likelihood that clinicians will adopt increased participatory practices at the level of individual clients' care.<sup>13,14</sup>

## DISCUSSION AND CONCLUSION

This model of consumer participation in an EIS has evolved over time. Its evolution has been largely driven by the young people accessing the service. Changing models of management over time, as well as developing clear processes for engaging and supporting young people, has enabled youth participation to be increasingly integrated into the organizational culture and practices.

Kidd *et al.* noted that some organizations are unsuccessful in their consumer participation endeavours, as they attempt to fit consumer participation into existing structures – for example, inviting consumers to existing working groups or committees.<sup>15</sup> The flexibility of OYH models of decision making and management has contributed to the success of this model. For some organizations, even where structures have been adapted to include consumer participation, consumers can be frustrated that decisions can occur too quickly, that they do not have time to ensure the representation of a wide range of stakeholder opinions, and they may feel their opinions are not being taken into account.<sup>16</sup> Decision-making processes at OYH (the commencement of a new intervention, new research project or production of a new psycho-education resource) are frequently slowed in order to enable consultation with Platform. The ongoing involvement of a wide range of stakeholders (i.e. as compared with the single, employed consumer consultant model) ensures the representation of a range of interests. Furthermore, the employment of a YPC ensures that responses to consumer feedback can be followed-up to ensure transparency and to minimize the risk of participation feeling tokenistic.

Although staff commitment to participation activities is likely underpinned by an acknowledgement that consumer participation improves the quality and acceptability of the service provided, it is also driven by staff members' past positive experiences of both 'bottom-up' and 'top-down'

consumer participation outcomes. For example, the Peer Support programme was developed by the members of the Platform team. The clinical programme was extensively consulted regarding boundaries, training and supervision for PSWs, as well as avenues for involving PSWs in routine clinical care. The programme has since become a valued component of services provided across OYH, to the extent that a research project collaboratively developed with PSWs has recently commenced, exploring the use of Peer Support interventions to support young people through discharge from the early psychosis programme.<sup>17</sup>

Although engaging young people in a diverse range of 'top-down' and 'bottom-up' initiatives presumes to ensure the representation of a diverse array of consumer interests,<sup>16</sup> OYH has engaged in minimal monitoring to ensure that this is the case. The provision of particular types of support (wellness plans, participation goals and training packages) may enhance the capacity of some consumers to participate and appears to enable the integration of new skills into their recovery journey (as described earlier).<sup>12</sup> However, these structures may act as a barrier to other consumers (e.g. consumers with a dual diagnosis, consumers with a dual disability and consumers from culturally and linguistically backgrounds). Although demographic information is a crude method of understanding the 'representativeness' of representation,<sup>18</sup> the steering committee continues to explore ways of supporting the involvement of any young person who is interested. The experiences and recommendations of other organizations who engage these populations in participation activities are being incorporated and new methods of participation are being trialled. We have begun using email to maintain contact with young people who cannot attend as many meetings as they would like, and email feedback is tabled at meetings. A client-driven, client-maintained website is being scoped, with a view to ensuring all consumers have access to adequate consumer-provided information about the service, as well as to avenues for participation. The annual consumer experience of care survey now includes information about how the organization – and Platform specifically – responded to feedback from the previous years' survey, in an effort to promote awareness of consumer participation activities and the importance of the consumer voice. The re-invigoration of the consumer newsletter is likely to further disseminate information on outcomes of participation activities to less-involved consumer stakeholders, hopefully enhancing accountability and encouraging participation

Although it has been noted that some professionals may experience consumer participation as undermining of their own roles,<sup>14</sup> there is some suggestion that the involvement of consumers in a range of roles is likely to reduce the split between service-provider and service-user, and support mutually respectful relationships.<sup>19</sup> Consumers at OYH adopt a range of roles in the organization (see Fig. 2), and the service-provider/service-user split is likely to be further reduced by continued efforts to involve staff in consumer participation business. The regular involvement of steering committee members in Platform meetings has recently been adopted, aiming to further build a sense of reciprocity and collaboration.

### Building an evidence-base

As a result of a lack of documented consumer participation models in EIS, the OYH youth participation model is continually evolving. Although each strategy for involving consumers in organizational decision making has its limitations,<sup>20</sup> using a broad range of strategies provides opportunities for the involvement of a broad range of consumers.<sup>21</sup> Where consumers are young people using an EIS, the provision of a range of support structures appears to enable the maintenance of a recovery focus, and the development of skills which young people can transfer into other settings.

Although the anecdotal evidence-base for consumer participation is strong, and the ideological evidence for the development and maintenance of comprehensive models for consumer participation is equally clear, there is a lack of rigorous and comprehensive evaluation of consumer participation.<sup>22</sup> Research undertaken in this area typically focuses on discrete participatory activities rather than overall programmes, or focuses on outcomes without addressing the soundness of models used.<sup>23,24</sup> Furthermore, research tends to focus *either* on outcomes for participating consumers *or* outcomes for service providers, without recognizing the range of potential impacts of consumer participation on a range of stakeholders.<sup>24</sup>

The current programme of youth participation at OYH is monitored for reach – in terms of engagement of consumers and in terms of uptake of activities – and barriers and enablers are continually identified and responded to. However, the absence of rigorous outcome evaluation results in the continued development of the programme, without ensuring a strong evidence-base. An evaluation protocol has been developed, which explores the participation experiences of Platform and PSW, the

experiences of the service amongst consumers who are not involved in Platform or Peer Support, and the experiences of consumer participation of clinicians in the service. Such an evaluation will provide valuable data about the impact of the programme for all stakeholders and, ideally, would be conducted regularly as a part of a continuous quality assurance process. Of particular interest would be whether young people find their experiences of participation truly 'empowering' and recovery-enabling; what drives non-participation among non-participating consumers; whether exposure to youth participation activities increases the likelihood of clinicians adopting participatory practices in their individual work; and whether youth participation does, in fact, increase the quality and acceptability of the service provided. Alongside other data such as extent and nature of activities undertaken over a given time period, this information would support the development of targeted strategies to increase the likelihood of empowering participation experiences, to reduce barriers to participation and increase avenues to participation. It may also see the changed emphasis on particular participation activities, development of new kinds of participation or policy change to increase the ways in which participation leads towards higher quality and more acceptable services. Furthermore, evaluation data would provide OYH with information to ensure that this programme can be adequately resourced to grow and evolve. It may also provide other EIS with evidence about how to enhance programmes of consumer participation so that they continue to support young people's recovery.

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