

Psychosis Survey 2024

Perspectives on
Breaking Stigma
& Improving Support

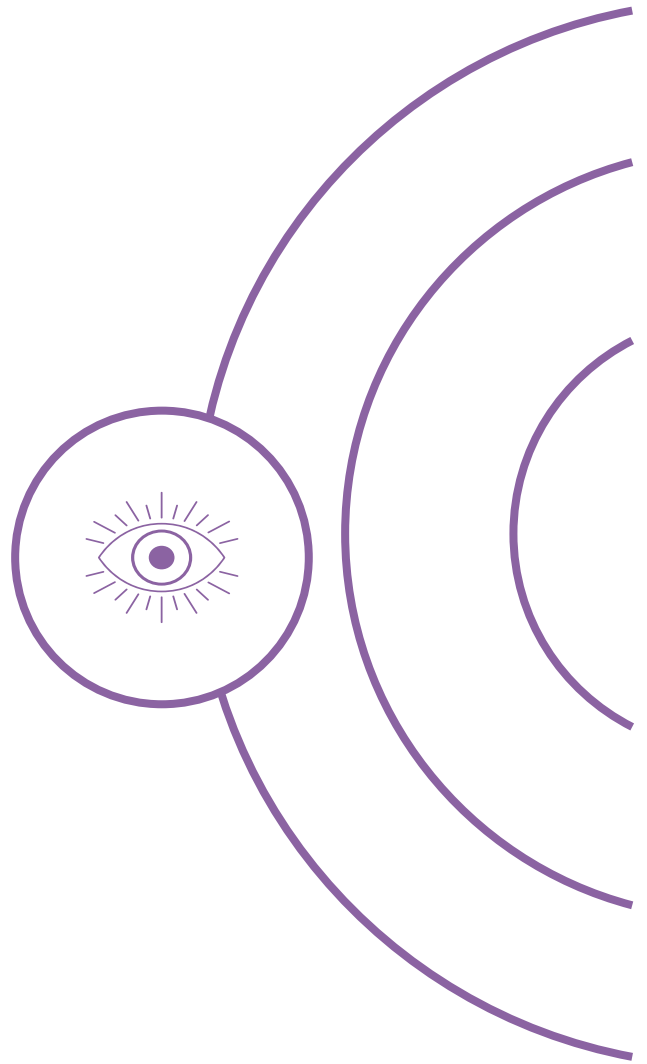
Listen.
Engage.

Psychosis Survey 2024

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Introduction

Psychosis is a condition that affects the way the brain processes information. During an episode of psychosis, a person's thoughts and perceptions are disrupted and they may have difficulty recognising what is real and what is not. Psychosis can present profound challenges not only to those directly affected but also to their families and supporters.



Recognising these challenges, Shine, Mental Health Reform, and the HSE National Clinical Programme for Early Intervention in Psychosis (EIP) conducted the Psychosis Survey 2024, gathering responses from 378 individuals.

The survey offers a deep dive into the lived experiences of people with psychosis, and their supporters, evaluating the effectiveness of current mental health services, exploring societal stigma, and identifying opportunities for systemic improvement. This report examines these findings comprehensively, discusses their implications, and proposes actionable recommendations.



The Survey

A national survey on the experiences of those living with psychosis was launched online on Thursday 23rd May 2024 and remained open for six weeks. This survey was promoted on Activelink.ie and shared across all Shine, Mental Health Reform and HSE National Clinical Programme Early Intervention in Psychosis platforms, network contacts and service users. Appendix 1 includes a copy of the Survey Questionnaire.

378

respondents

28%

increase from 2023

Respondents

The 2024 survey witnessed significant participation, with 378 respondents, a 28% increase from the previous year. Of these:

- 188 respondents (49.7%) had personal experience with psychosis.
- 190 respondents (50.3%) supported someone with psychosis

Therefore, the survey highlighted the dual perspectives of individuals and family members/supporters.

Figure 1: Age profile of survey respondents

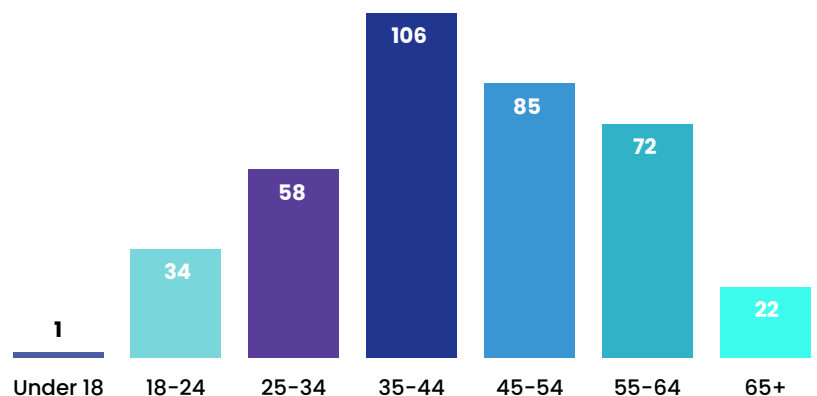
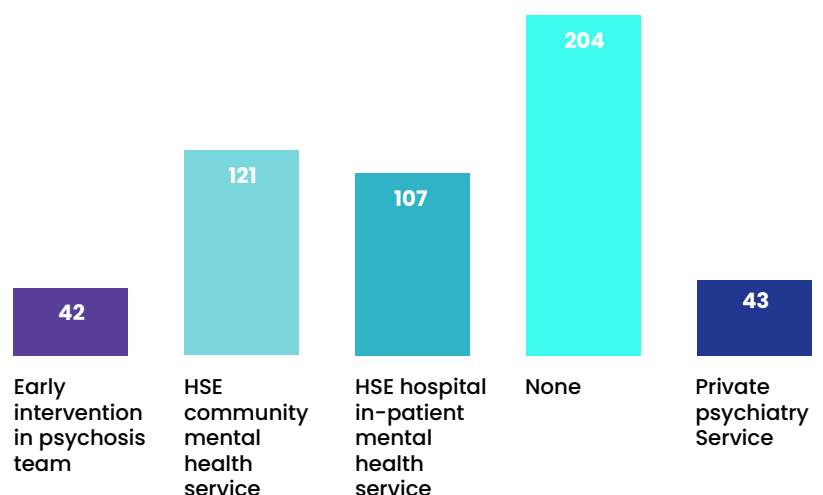


Figure 2: Types of Mental Health Services Accessed by Respondents





Psychosis Survey 2024

KEY FINDINGS

Access to Services

1

Access to Services

EIP vs. Non-EIP Services

One of the most striking findings is the disparity in access to mental health services between those utilising Early Intervention in Psychosis (EIP) services and those relying on general mental health services.

EIP Services

(11% of respondents):

- 42.9% found access to mental health services “very easy.”
- 52.4% reported ease in obtaining assessments.
- 45.2% found accessing information on symptoms and treatments straightforward.

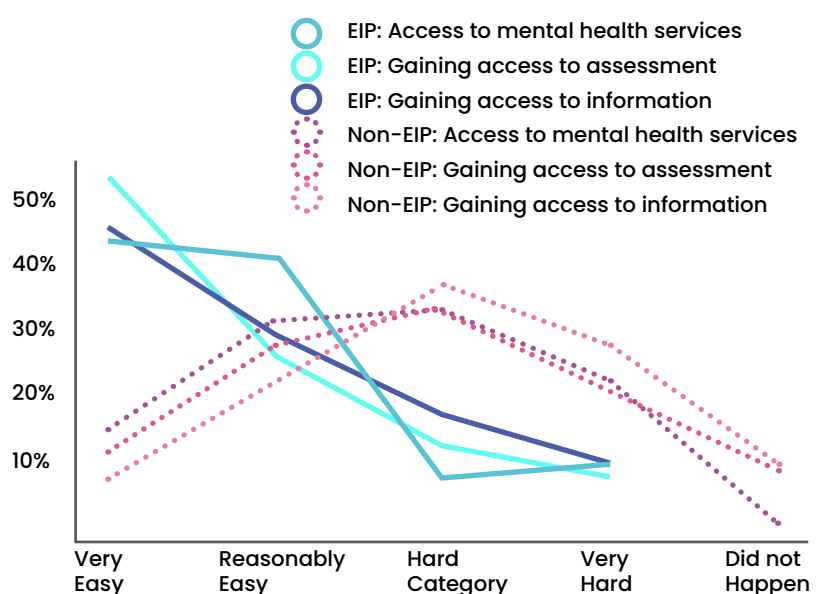
General Mental Health Services

(89% of respondents):

- Only 14.4% found access to services “very easy.”
- A significant 32.6% rated access as “hard” and 22% as “very hard.”
- Information access was challenging for 36.4% and “very hard” for 27.3%.

The findings illustrate the transformative impact of specialised services like EIP. Accessing EIP often provides individuals with early, targeted support, improving outcomes and reducing the long-term burden on mental health systems. Conversely, the struggles faced by those in general mental health services reflect systemic gaps, such as insufficient funding, lack of trained personnel, and limited geographical coverage.

Figure 3: Contrasting access experiences between EIP and non-EIP service users



Psychosis Survey 2024

KEY FINDINGS

Supports Offered



2

Supports Offered

EIP vs. Non-EIP Supports

EIP services consistently provided more comprehensive and targeted support:

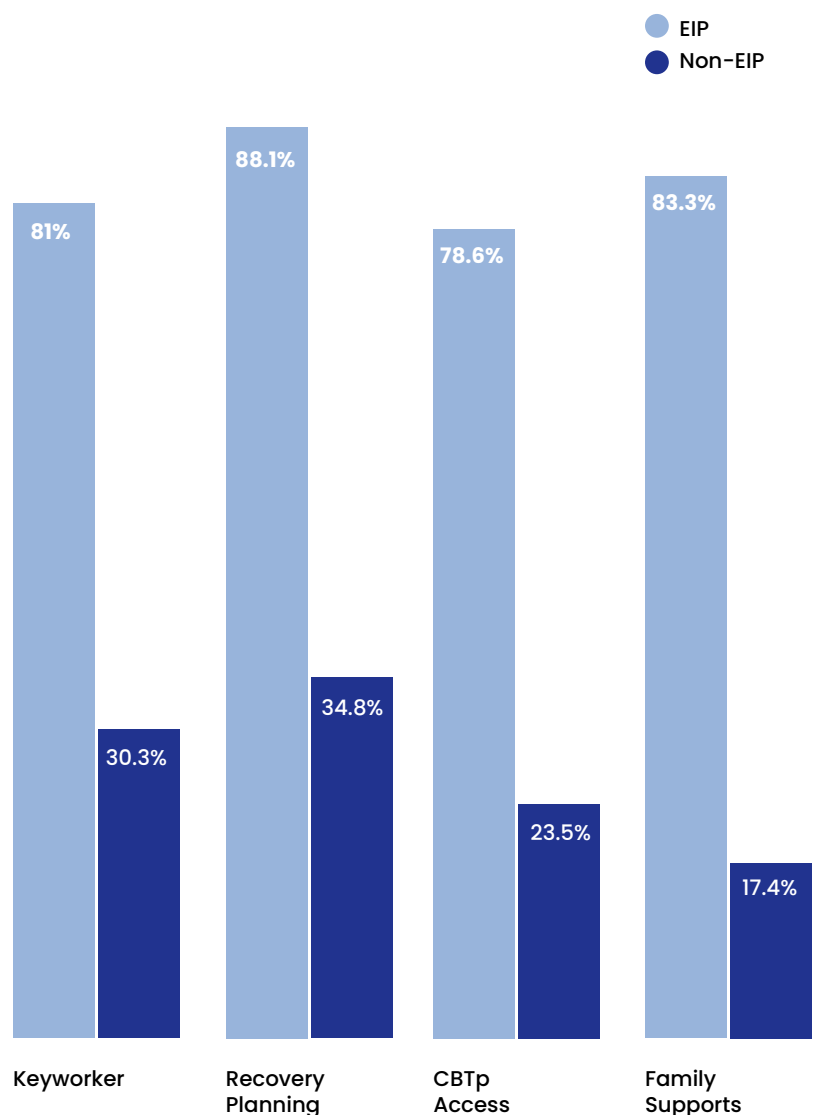
- 81% of EIP users reported that they had a named keyworker, compared to 30.3% of non-EIP users.
- 88.1% of EIP respondents received recovery planning support, against 34.8% in non-EIP services.
- Psychosis-specific psychological interventions were offered to 78.6% in EIP services, compared to only 23.5% in general services.



The word
psychotic is used
interchangeably
with the word
psychopath.

These disparities underscore the importance of EIP models. Recovery-oriented practices, such as the assignment of keyworkers and the availability of targeted evidence-based interventions, empower individuals and their families to navigate psychosis more effectively. Non-EIP services often lack such structured approaches, leading to fragmented care.

Figure 4: Comparison of supports available in EIP vs non EIP services



Psychosis Survey 2024

KEY FINDINGS

Role of Community and Charitable Organisations



3

Role of Community and Charitable Organisations

Community and voluntary organisations play a crucial role in complementing state-provided services:

- 40% of respondents with lived experience had accessed organisations like local counselling services, Shine, Grow, and Aware.



Meeting other parents going through the same thing helped. Learning how to support my daughter create a good relationship with her voices.

Figure 5: Respondents with lived experience of psychosis who had accessed community and charity organisations

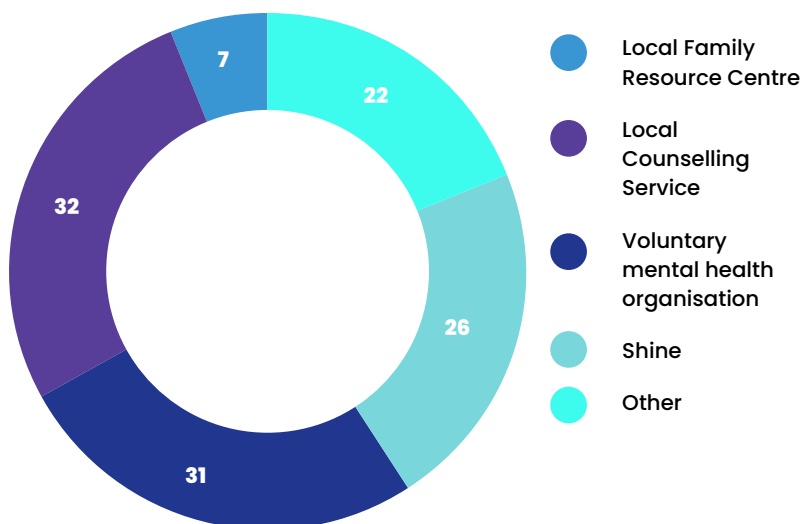
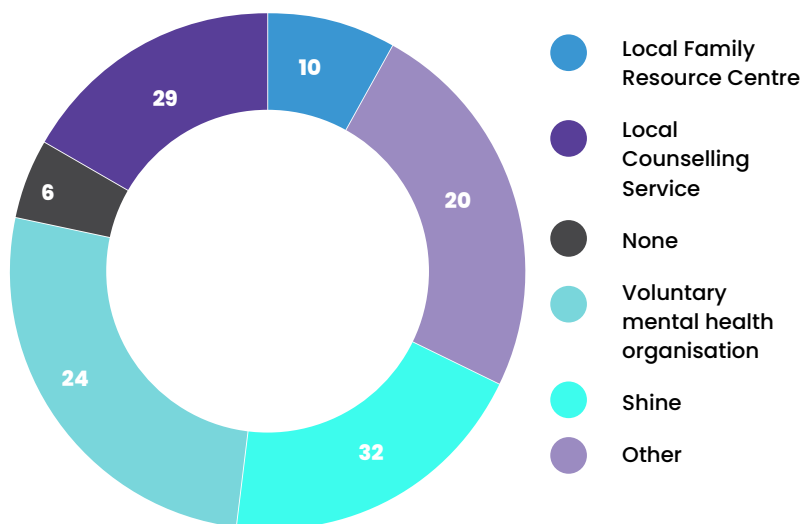


Figure 6: Respondents who were supporters who had accessed community and voluntary organisations



These organisations often fill critical gaps in the mental health care system by providing localised, accessible, and empathetic support. However, reliance on such organisations highlights systemic inadequacies, as these services are often overburdened and underfunded.



Psychosis Survey 2024

KEY FINDINGS

Stigma and Discrimination

4

Stigma and Discrimination

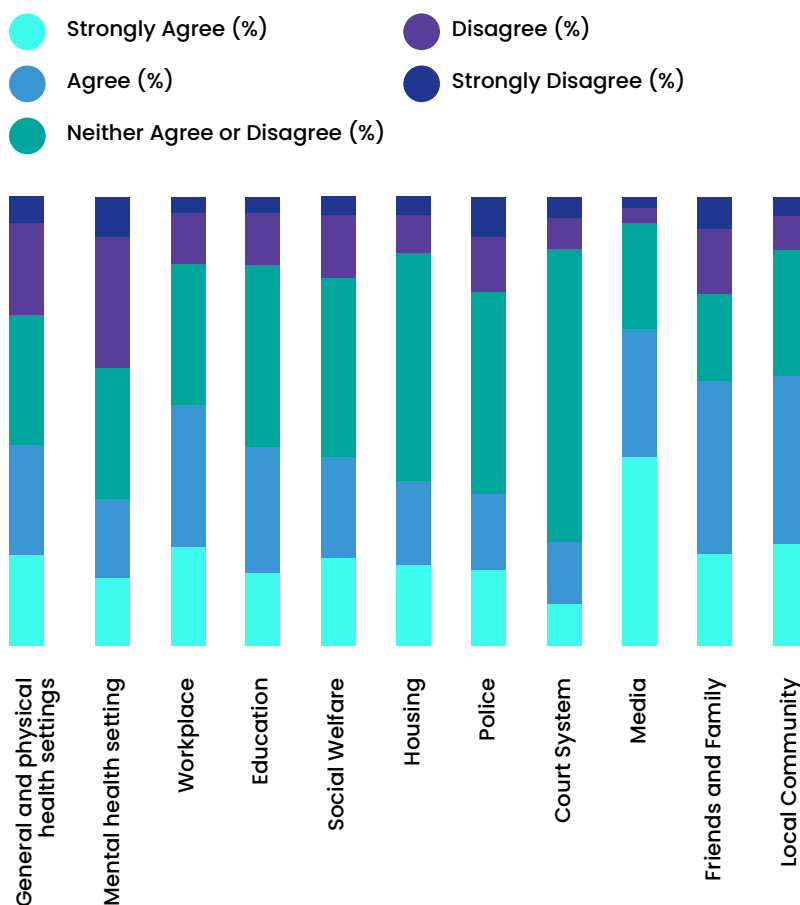
Settings of Stigma

Respondents reported stigma across various societal domains:

- General Health Settings: 44.9% experienced stigma.
- Workplace: 54% reported stigma, impacting job security and professional relationships.
- Education: 44.4% faced discrimination, hindering academic progress.
- Media: 70.9% agreed representations of psychosis in media were stigmatising or discriminatory.

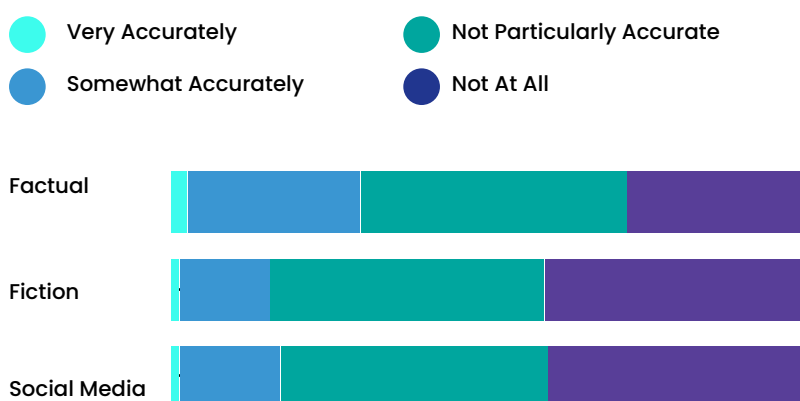
Stigma remains one of the most significant barriers to recovery. It not only isolates individuals but also discourages them from seeking timely help. Media portrayals play a pivotal role in shaping public perception, and inaccurate or sensationalised narratives exacerbate discrimination.

Figure 7: Stigma and discrimination experienced by people



Audiences are exposed to many media types. These findings suggest progress in the accuracy of factual media while fictional representations of psychosis and non-professional social media content may require more targeted interventions.

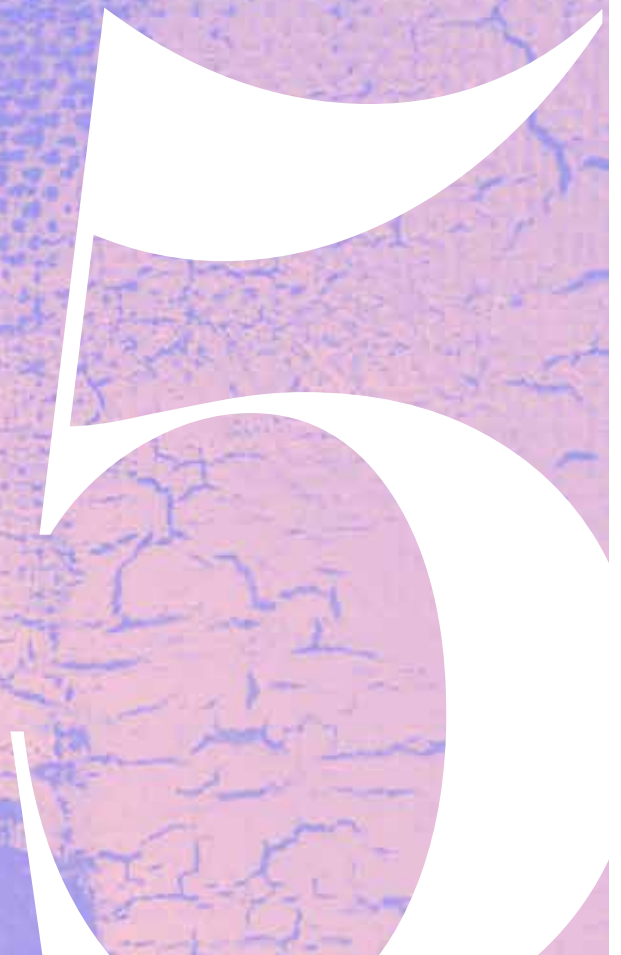
Figure 8: How accurately do you see the experience of psychosis portrayed in Irish media?



Psychosis Survey 2024

KEY FINDINGS

Perspectives on What Helps Most



5

What people reported as being most helpful to them in managing psychosis

The key themes from people with lived experience included:

- Many people identified individual mental health staff including nurses, occupational therapists, peer support workers, psychiatrists, psychologists and social workers as who they found to be supportive.
- People who attended EIP services also identified EIP keyworkers, Employment Support workers, psychotherapists in addition to the staff identified in other teams.
- Community organisations, particularly Shine, were identified in the qualitative feedback as being of great support with their recovery programme receiving frequent mention.
- Programmes run by mental health teams often in collaboration with community organisations were also mentioned frequently e.g. Woodlands for health, sea swimming, exercise groups, walking groups.

- Peer support and meeting other people who have had similar experiences and are working on recovery was identified as valuable.



My key worker and CBT received has been really helpful and the team are so kind. Also, the employment supports received to help me with getting back to work and adjusting to work while recovering were really beneficial.

The key themes from people who support someone living with psychosis included:

- Having someone to listen and engage with them. Some identified staff in the mental health services as doing this well. Others identified staff in community organisations as meeting this need better.
- Family intervention and support groups were identified both in the HSE e.g. Behavioural Family Therapy and in organisations like Shine e.g. Family Recovery Group.
- Supporters identified being provided with information on symptoms, diagnosis, strategies to assist but also advise on how to mind themselves and their recovery as being very helpful.
- Peer support was identified as very valuable to families and other supporters.



Listening to my experience about the challenges of supporting my family member who is experiencing psychosis (what I found was helpful to them/what wasn't) and how that made me feel. In a sense these conversations allowed me to do some re-focusing to gain more understanding on what I could do to better support my relative, but also to realise that do be able to provide 'good' support I also needed to focus on myself

Psychosis Survey 2024

KEY FINDINGS

Priorities for Improving Care



6

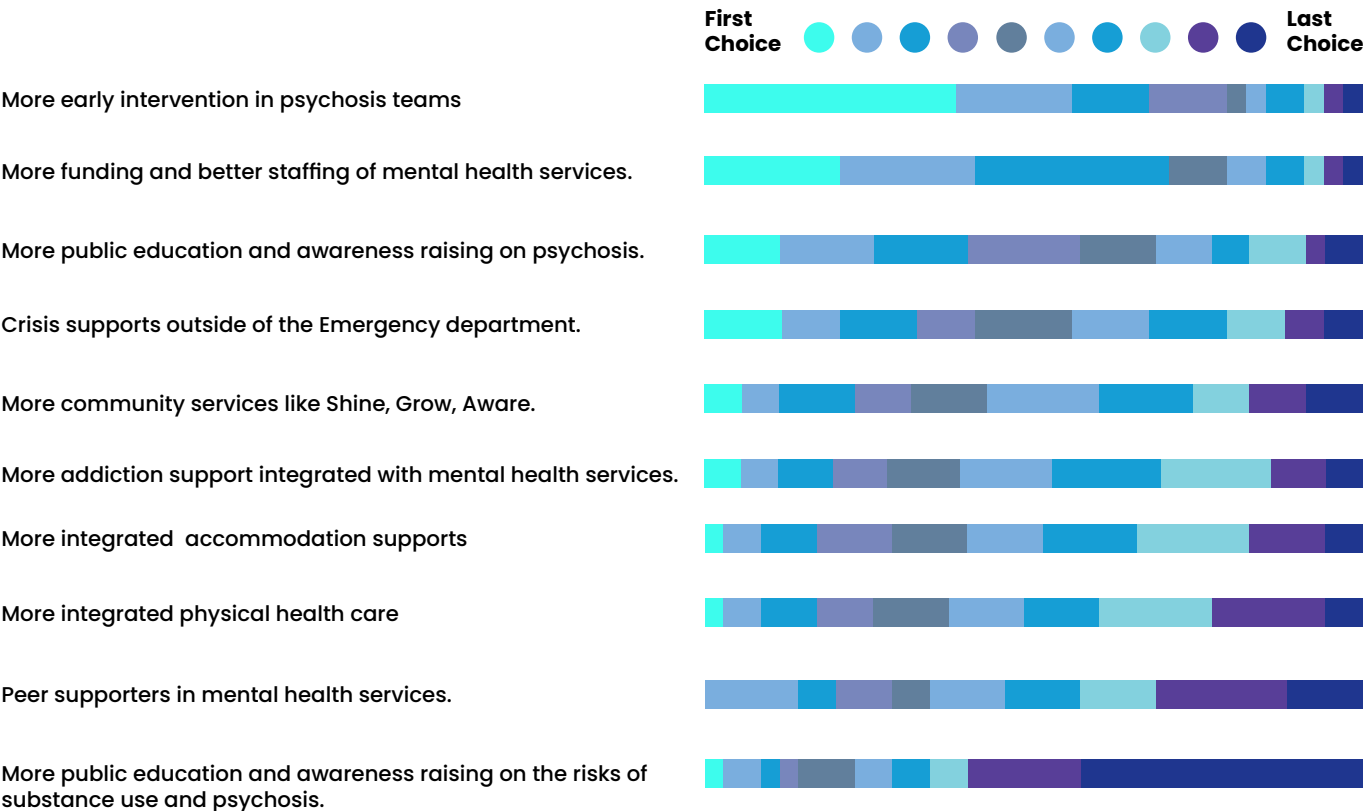
Respondents’ priorities for improving care

Respondents were asked to rank from a list of ten, their priorities for improving care, with the top recommendations being:

- Expanding EIP services (42.3% ranked as highest priority).
- Increasing funding and staffing for mental health services.
- Raising public awareness about psychosis.
- Developing crisis support outside emergency departments.

The recommendations reflect a growing consensus on the need for systemic reform. Expanding EIP services would address access disparities, while increased funding and staffing are foundational to sustainable improvements. Public awareness campaigns targeting stigma could foster a more supportive society, and alternative crisis services would reduce the strain on emergency departments.

Figure 8: Respondents ranked their priorities for Improving care





Psychosis Survey 2024

KEY FINDINGS

Recommendations

7

Recommendations

A.

Expand Early Intervention in Psychosis (EIP) Teams

Scaling up EIP services nationwide is critical. These teams should provide:

- Comprehensive care plans with assigned keyworkers.
- Psychosis-specific interventions, including CBTp (Cognitive Behavioural Therapy for Psychosis) and family therapy, integrated physical health and employment support.

B.

Increase Funding and Staffing

Adequate investment in mental health services in the statutory and voluntary sector is essential to:

- Reduce wait times for assessments and interventions.
- Ensure equitable access across rural and urban areas.
- Understanding that services delivered cannot be a “one size fits all”.

C.

C. Combat Stigma Through Public Education

Collaborative campaigns between healthcare providers, schools, and media outlets can:

- Educate the public on the realities of psychosis.
- Highlight recovery success stories.
- Dispel myths and stereotypes.

D.

Establish Crisis Support Outside Hospital

Developing crisis supports outside hospitals can:

- Provide specialised care in a less intimidating environment.
- Prevent delays in treatment during



E.

Strengthen Community-Based Organisations

Community organisations should receive increased funding to:

- Expand their reach and programme offerings.
- Support family members and caregivers alongside individuals.

F.

Integrate Addiction and Mental Health Services

Integrated models can address co-occurring conditions, ensuring:

- Comprehensive treatment for psychosis and substance use.
- Greater continuity of care.

G.

Enhance Housing and Employment Support

Collaboration between housing services, employers, and mental health providers can:

- Stabilise living conditions for individuals with psychosis.
- Foster inclusive work environments.



**In GROW
groups I have
experienced
support
from other
people with
experience
of psychosis.**



Conclusion

The Psychosis Survey 2024 underscores the critical disparities in mental health care, particularly emphasising the benefits of Early Intervention. This survey has illuminated the profound impact of specialised interventions, which not only enhance access to care but also provide targeted support that significantly improves outcomes for individuals with psychosis. While EIP services have shown great promise, the overall landscape of mental health care still faces considerable challenges, such as funding limitations, staffing shortages, and a pervasive stigma that continues to hinder the efficacy of mental health service delivery.

The findings from the survey highlight a pressing need for systemic reform in mental health care. Expanding the reach and availability of EIP services, increasing funding and resources, and educating the public to combat stigma are paramount to improving the mental health care system. Such measures would not only address the immediate needs of individuals with psychosis but would also contribute to a more sustainable and equitable health care system that can better manage the complexities of mental health conditions.

Community and voluntary (charitable) organisations play a vital role in bridging the gaps in state services, offering essential localised and accessible support. There is a compelling need for increased support and integration of these organisations into the broader mental health care framework, ensuring they receive adequate funding and recognition for their critical role.

Organisations such as Shine, are not available in some parts of the country and service provision is overly reliant on fundraising to supplement state funding.

In conclusion, the 2024 Psychosis Survey calls for a committed, multi-faceted approach to mental health reform. By prioritising the expansion of EIP services, enhancing support structures, and actively reducing stigma through public education, Ireland can significantly improve the quality of life for those affected by psychosis. Such initiatives require collaboration of healthcare providers, policymakers, community groups, and the media to foster an inclusive, supportive environment that promotes recovery and reduces the long-term societal and economic impacts of psychosis.



Lived Experience Testimonies

Stigma and Discrimination

"When something horrible happens the media and other's immediately say that person must have been mentally ill, this is a disservice to people with mental illness and creates a climate of fear, there are bad people in the world stop labelling them mentally unwell."

"Eastenders has done very good representation of the Psychosis experience and created conversations about the illness."

"Language used, crimes relating to mental health sensationalised.... image of psycho killer amplified. No coverage of positive recovery stories."

"I have been involved in a number of newspaper articles trying to raise awareness for psychosis and recovery and also on National radio interviews and also share a lot about it through social media so have come across some others who do the same. I haven't seen any accurate representations through film or tv."

"When the word psychotic is used interchangeably with the word psychopath."

"Psychosis is not "sexy". People are afraid to discuss it. Maybe Denise in Eastenders was a good example. I never read about psychosis on social media."

"Psychosis is often depicted as criminal behaviour related not as an illness to be treated."

"My feelings about the media and their coverage of people with psychosis is that they heighten the drama of it all never thinking of the person or the families pain and trauma in seeing their family member in a state of psychosis and I also include A&E departments in this as my son was having a psychotic episode and we had to wait for a mental health-assessment between patients on trolleys in a hallway while they are eating their breakfast."

"When incidents occur, Mental health is rolled out immediately. This further causes stigma and a sense that people with a Mental Health Illness are dangerous rather than needing support and empathy."

Lived Experience Testimonies

Stigma and Discrimination

“Media reports focus on isolated negative incidents. No representation of people living with psychosis who are successful and contributing positively to their community.”

“The media (news) will give short snippets of information which generally focus on the most extreme aspects or the victims experience. Movies are dramatised so naturally will not an intention based on what they think viewers might like and social media, i personally feel, confuses mental illness with poor mental health. So, its good people are talking about their mood being low and some days feeling de-motivated but they are comparing this to mental illness where a person needs a more formal intervention as a result of how they are feeling.”

“Almost all forms of media highlight only negative outcomes of those living with psychosis or having violent psychotic episodes which end in harm to others. The mental illness is incredibly stigmatised and rarely are the lack of supports for patients and friends/family highlighted.”

“Denise in EastEnders was relevant to our experience.”



Lived Experience Testimonies

Perspectives on what helps most

"My key worker and CBT received has been really helpful and the team are so kind. Also, the employment supports received to help me with getting back to work and adjusting to work while recovering were really beneficial."

"My mental health nurse, she was incredible at talking to me and guiding me through treatment."

"Our psychiatrist consultant is great. Behavioural Family Therapy is excellent. Day hospital was excellent."

"The first time I had psychosis, the medication helped the most."

"In GROW groups I have experienced support from other people with experience of psychosis."

"Also in X mental health service there is a Hearing Voices group. In both groups people with lived experience share. So not alone and one picks up wisdom."

"Peer support in X and Y Mental Health Services. The Next Step in X run creative classes for Mental Health."

"I discovered Shine via social media. It was the first organization I found that catered to supporting family members in Ireland. Shine provided me with education on symptoms and caring for someone with psychosis, as well as access to other support organizations and resources. This helped me better understand how the mental health services system works in Ireland and opened the door to additional support."

"Shine and HSE support programmes for family members of a person with psychosis."

"Meeting other parents going through the same thing. Learning how to support my daughter create a good relationship with her voices."

"When my son was involved in X mental health services, I received a lot of support from local mental health services they were always helpful and there for my and his family. My son then moved to a different mental health service, and I feel this service is totally unsupportive to family members."

Lived Experience Testimonies

Perspectives on what helps most

"If it wasn't for the support of Shine, I probably would not have been able to cope having a family member with severe psychosis who still after years has not been treated."

"Listening to my experience about the challenges of supporting my family member who is experiencing psychosis (what I found was helpful to them/what wasn't) and how that made me feel. In a sense these conversations allowed me to do some re-focusing to gain more understanding on what I could do to better support my relative, but also to realise that to be able to provide 'good' support I also needed to focus on myself."



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