

# Mental Health Carers Consultation /Carers Self Advocacy Group



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11 February 2022



# Consultation background/timeline

- Mental Health Carers Experience Project funded by Thrive Edinburgh started December 2020
- Project aims and outcomes
- Consulted with 70 carers during June – September 2021
- Supported by four trained Volunteer Peer Facilitators
- Data analysis and report writing October 2021 – January 2022



# Key findings



## **Challenging Circumstances of Carers**

“I have only recently been informed of a support service for carers even though I have been caring for a person with a mental health condition for a number of years. I feel my role as a carer and the strain it has put on me has not really been taken into consideration.”

## **Poor attitudes and accountability of professionals**

“There is NO accountability and the usual “lessons will be learned” message is empty and pitiless to families concerned”

“They ( carers) know their loved one better than any health professional , yet they are ignored, patronised or placated with no good results...”



## **Lack of carer recognition and involvement**

“Exasperated. Desperate. Completely unsupported. Infuriated at the lack of clarity on how to access services or what you can expect them to provide, and putting all responsibility back on to informal carers and seriously ill individuals.”

“My feeling (is) of being a stranger to the services. Services are also strangers to each other and pass the buck between them!

## **The power of good support and engagement**

“It was really helpful to be offered a one off carer appointment to give me a chance to talk to staff on my own about what was happening and for them to signpost me to carer services such as VOCAL”





## What could help to improve the current situation?

(I would like) “professionals who are respectful. Professionals that seem to work alongside carers”

“I think getting some help at the time quite bluntly. I mean whenever the help arrives its welcome but it needs to be timely”

90% of carers involved in the consultation wished to be treated with respect, compassion and honesty and to be included as an equal partner in care. Carers would like professionals to be more aware of the impact their attitudes and systems can have.



“I would have liked some one to have explained things better, more support for me . It would have helped us all understand it better”

(I would like) “a service which listens and responds to concerns raised and which works together with the carer and realises the carer is an important member of the support team who has useful information about the person being cared for”

“All organisations involved in the care of a person should be interconnected and aware of each other”

The need for better communication both from the professional for the carer to be able to share their experiences of the cared for person was very clear. Carers would like sufficient information to enable them to carry out their caring role more effectively and better communication and engagement between services especially acute and community .



# Conclusions

- Preventative approach to identifying and supporting carers
- Systemic change within services and across acute and community provision;
  - Review of systems, processes and common practice at all stages of the carers journey within a service
  - Staff training around carer involvement
  - Greater understanding of the carer role and improved inclusive and empathic behaviours
  - Consistent involvement of carers as equal partners in care including provision of sufficient information about the persons condition to enable effective care at home
  - Improved “two way” communication between professionals and carers



# Carer involvement development work - some early successes !

- Monthly Acute services carer support group established at Royal Edinburgh
- 1-1 Carer appointments, immediately following admission, implemented within Royal Edinburgh Acute Services
- 9 Think Carer Training Sessions co-delivered to approximately 75 Acute Services staff since October
- Supporting the development of Dementia carers support group
- Ongoing relationship building within Royal Edinburgh Acute Services





# Plans for 2022



- Engaging and relationship building with those services commented on in the data, including Thrive Welcome Teams to duplicate work begun at Royal Edinburgh Hospital
- Work begins with Royal Edinburgh Acute Service on reviewing carer involvement protocols, documentation and processes – in co production
  - Development of carer involvement pathway - in co –production
  - Development of carer “charter/promise” for Acute Services – in co-production
  - Development of carer involvement toolkit – in co-production



# 2022 continued

- Development of focussed feedback consultation – potentially around stages of engagement with services or with specific carer communities
- Planning for continuous broad carer feedback via carer support team/online polls or similar
- Work with Thrive to include carers stories from consultation within Thrive storytelling resources
- Work with peer facilitators to review project volunteer role



# Vocal Carers Self Advocacy Group



# Typical group meeting .....

- Welcome
- Mindfulness opening practice
- Brief review of self compassion practice
- Since we last met I have ....?
- Focus of today's group :
  - self motivation
- Homework/practice !

Mindfulness closing practice



# Why a self advocacy group ?

“I’ve enjoyed everything vocal has offered me so far and this group in a strange way embeds all of this. I’m slowing accepting my son does in-fact need additional support while awaiting an autism diagnosis. I’m also accepting I am a carer for him. I feel I’m taking myself more seriously being a carer (it is for me ,my full time job) so getting the tools I need to do the job to the best of my ability, is extremely important to me. This is after all a new and difficult job. Not one I ever thought I’d be doing. I feel the need to find out how getting my voice heard could benefit him especially when talking to professionals and nursery staff in Child planning meetings etc.”

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“The group makes me realise I am not alone or the only person in this situation. We listen to each other, give each other motivation and support. I feel very isolated, this is the only social time I get for myself. I love the group as I learn an awful lot, sharing experiences with each other and also I have learned not to be so hard on myself. The group has made a positive difference in my family’s and my life. I’m able to think a little clearer now about my carer relationships.”



# Next steps

- Introduction to making my voice heard - next course 2022
- Introduction to helping carers make their voices heard - April/May 2022
- Grow the Self Advocacy Group
- Group members get more involved in Thrive project





Thoughts, questions, comments ?





[vocal.org.uk](http://vocal.org.uk)



VOCAL - Voice of Carers Across Lothian  
Scottish Charity: SC020755 | Company Registration: SC183050

