'It should be for people themselves whether they want to take part or not. The organisation should not get involved' – a response to Williams



The IRN is a group of self-advocates, supporters and academics who do research on issues important to people with learning disabilities in Ireland.



In 2019, one of the academic supporters of the IRN was invited to write an article about gatekeepers in research. She asked the IRN members if we wanted to write the article together and a few of us agreed.



This article was a response to another article written by Peter Williams.



Gatekeepers are people who control contact between people. For example staff working in services often decide if a researcher can talk to people with learning disabilities.



In the IRN:

- self-advocates talk to people who take part in research because "we understand better other people with learning disabilities"
- Support staff help self-advocates by contacting gatekeepers.



Peter Williams joined us by Skype and explained his article.



A group of us met twice and we talked about some of the issues Williams found in his research and we thought about some solutions.



'it should be for people themselves whethe want to take part or not. The organisation not get involved' – a response to Williams We have published our response here In the European Journal of Special Needs Education. You can see it here:

http://www.fedvol.ie/Inclusive Research Network IRN/Default.241.html



Gatekeepers often say "no" to our supporters when we try to talk to people in their services.

This happened to Williams many times.

Williams says that gatekeepers say no to protect people with learning disabilities from researchers.



We think:

- They [gatekeepers] are taking independence away from people with learning disabilities
- It should be for people themselves whether they want to take part or not. The organisation should not get involved.



Like Williams, we also worried about approaching people with learning disabilities and whether it is legal.

Sending a video about the research is a good idea, because it is true that people can take advantage. The supporter would know what is expected of them.

Williams says that even when we send the video, the gatekeepers can choose not to show it.



Self-advocacy groups are another way of getting to talk to people with learning disabilities.

 Talking to people in familiar places makes it easier for researchers and for people with learning disabilities.



 Meeting people before we talk to them about research is another good idea.



 The main problem is to get to talk to people with learning disabilities for the first time. They are generally in services and staff protect them.



 The attitudes of staff and managers need to change so they are more willing to let researchers talk to people with learning disabilities.



- Staff and managers have to see people with learning disabilities as:
- Able of making their own decisions
- Able to take part in research
- People who may need support to make decisions and to take part in research



- Staff and managers should be trained about:
 - o people with learning disabilities taking part in research
 - o decision making by people with learning disabilities
 - advocacy



Organisations who give money for research and groups like the IRN can do this training.











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Garcia Iriarte, E., Salmon, N., Donohoe, B., Leddin, N., Body, J., O'Toole, C.A., McMeal, K., O'Reagan, H., & Barrett, M. (2019). 'It should be for people themselves whether they want to take part or not. The organisation should not get involved' – a response to Williams. European Journal of Special Needs Education. https://doi.org/10.1080/08856257.2019.1687560.