



Abstract Title: Doctors and us: A community-based project by the Inclusive Research Network

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Introduction

The [research team] is a group of people who talk and do research about intellectual disabilities since 2008. People in the [research group] include self-advocates, service providers, academic researchers and community groups.

People with intellectual disabilities endure health inequalities (Emerson et al. 2012) and have poorer health than most others (Robertson et al 2014). They face many barriers to healthcare access including: physical, societal, and language issues (Emerson et al. 2012; WHO 2011). A big Irish study about aging (IDS-TILDA) found that 1 in 3 adults with an intellectual disability have trouble making themselves understood when speaking with health professionals (McCarron et al., 2011).

Although there is a small amount of research about the health of people with intellectual disability, no studies were co-led by self-advocates.

Objectives

This project aimed to (1) describe people with intellectual disabilities' experiences going to see the doctor and (2) to identify ways to help people feel more at ease at doctor's visits.

Methods

We agreed that focus groups were the best way to meet the project aims. We agreed on the questions to ask and used many pictures in the focus groups to get people talking about what it is like to go to the doctor's office. Members of the [research team] and supporters took part in workshops to learn how to co-lead focus groups.

Two focus groups were completed in 2017 with a total of 13 people with intellectual disabilities (6 men and 7 women) and 3 supporters taking part. The average age of those taking part is 51 years old. We expect 5 more focus groups to run in spring 2018.

Findings

Our early findings show that there are many good things about doctors' visits like feeling welcome, having easy access to the office and feeling looked after. People wanted to have easy read handouts about their health to take away after a doctor's visit. There were concerns that included: long waiting times and having no choice in what doctor you see. People talked about the support they had for doctors' visits but were concerned when doctors talked to staff and not to the person.

Conclusion

People with intellectual disabilities want to be able to talk easily to their doctors. They have the right to know what is happening to their bodies and to feel looked after.

References

- Emerson, Eric., Baines, S., Allerton, L., & Welch, V. (2012) *Health inequalities and people with learning disabilities in the UK*, IHaL. Available: https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S., & McCallion, P. (2011). *Growing older with an intellectual disability in Ireland 2011: first results from the intellectual disability supplement of the Irish longitudinal study on ageing*. Available: https://nursing-midwifery.tcd.ie/assets/research/doc/ids_tilda_2011/ids_tilda_accessible_report_2011.pdf
- Robertson, J., Hatton, C., Emerson, E. & Baines, S. (2014). The impact of health checks for people with intellectual disabilities: an updated systematic review of evidence', *Research in Developmental Disabilities* [online] 35(10), 2450–2462. Available: <http://dx.doi.org/10.1016/j.ridd.2014.06.007>
- World Health Organisation (2011) *World report on disability*. Available: http://apps.who.int/iris/bitstream/10665/70670/1/WHO_NMH_VIP_11.01_eng.pdf

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