Global Partnerships: Enhancing Research, Policy and Practice

Congress Abstracts

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A journey of empowerment in inclusive research
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Aim: Inclusive research in Malaysia is scarce. We reflect on our first experiences with inclusive research despite the challenges given to us. Method: We were given opportunity to speak and listen to, and contribute to a study as individuals with intellectual and developmental disabilities. We shared our experiences by writing journals, and giving our ideas to the study. We learned to collect data and analyse data through experiential learning. Results: As research partners, we learned to reflect and think more. We also learned to discuss and write more. It is a journey of empowerment where we share power whilst producing knowledge as a team. Participating in this research project has enabled us to practice self-advocacy in a proactive manner towards collaborative learning. Conclusions: It is an enriching process. We need to learn and work together as a team. We believe in ‘nothing about us without us’ and our rights to research to promote social change and achieve full inclusion.

A winning solution as peer mediators
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Aim: To explore the learning progress of peer mediation by people with intellectual and developmental disabilities in resolving disputes among their peers. Method: A 90-hour peer mediation training was conducted in 3 phases using experiential learning approach. After which we conducted peer mediation to our members who have conflicts among themselves. We recorded our learning points in our daily journals from training to real setting. We reflected on our own journals and research documents, and discussed our learning points in focus group discussions and analysed our data in our review meetings. We reviewed our recorded peer mediation to improve our peer mediation skills. Results: It is a progressive self-manipulation learning process for us as peer mediators. We learned to accept our limitations and work together as a team. Our confidence level was increased as we learned to manage disputes among our members. Conclusions: It is possible to support our members in resolving their disputes in a systematic and constructive manner. We learned the importance of working interdependently among ourselves as a winning solution.

Improving health advocacy and health outcomes in adolescents with intellectual disabilities
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Aim: Adolescents with intellectual disabilities (ID) experience poorer health than their peers in the general population. We tested whether a health intervention package led to increased health advocacy and improved healthcare for this group. Method: A clustered randomised controlled trial (RCT) was conducted in adolescents with ID in Queensland, Australia. The intervention package consisted of health education, a health diary and health check. Health advocacy was measured by a peer questionnaire. Health promotion, disease prevention and case-finding activities were extracted from general practitioner records for one year.

post-intervention. Results: Carers of 592 adolescents completed the baseline survey. Advocacy and health outcomes were available for 385 (65.5%) and 435 (73.5%) participants respectively. Adolescents allocated to the intervention were more likely to attend the doctor on their own, ask questions and explain their health problems without help. They were more likely to have their vision, hearing, blood pressure and weight checked by the doctor. There were no differences between health intervention and usual care for identification of new diseases. Conclusions: The school-based intervention package improved advocacy and led to increased healthcare activity in adolescents with ID.

The health of adolescents with intellectual disabilities
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Aim: Few studies have reported the prevalence of co-morbid conditions in adolescents with intellectual disabilities (ID). This study investigates the prevalence of co-morbid conditions among adolescents undertaking a health check. Method: Cross-sectional data were obtained from parent/carer-reported information extracted from a health screening tool used in a wider trial of adolescents with ID in Queensland, Australia. Before visiting a general practitioner, the parent or carer completed the first section of this tool to record a complete medical history, after which the general practitioner conducted a thorough medical review. Results: Data were obtained for 176 participants aged 11-19 years at the time of the health check. Parents/carers report high levels of co-morbidity in adolescents with ID in their care.

The Autism CHAP: A comprehensive health assessment program for adults on the autism spectrum with intellectual disabilities
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Aim: Adults on the autism spectrum with intellectual disabilities (ID) experience unique health-related needs and difficulties accessing adequate health care. They also exhibit poorer physical and mental health outcomes in comparison to the general population. This project evaluates the feasibility and acceptability of a comprehensive health assessment program (Autism CHAP) for adults on the spectrum with ID. Method: This project is guided by an advisory group including adults on the spectrum. Adults on the spectrum with ID will visit their general practitioner/nurse to complete the Autism CHAP. Up to 35 semi-structured interviews will be conducted with participants including the adults, their support persons and health professionals. Interviews will be digitally recorded, transcribed verbatim and analysed using thematic analysis. Results: Preliminary feedback from advisory group members suggests the Autism CHAP is appropriate and feasible for use with adults on the spectrum with ID. The results of the thematic analysis will be described. Conclusions: The Autism CHAP has the potential to improve health outcomes for adults on the spectrum with ID.