

Appendix

Appendix 1

Search Strategy

PICO Framework used to develop systematic review

a. P (Participants): Individuals with LD in middle age (40+ years), being cared for by an unpaid ageing carer (65+years)* within the UK.

b. I (Intervention): Short term/long term support available to individuals living with LD at times of crisis, e.g. when their ageing carer gets injured or seriously ill.

c. C (Controls): Individuals living with LD when their ageing carer gets injured or seriously ill getting no support or getting an alternative e.g. early intervention to prevent such crisis

d. (Outcomes): - The identification of existing services, infrastructure, funding, policies and/or interventions (both short term/long term) within the UK to support individuals with LD who are cared for by an unpaid ageing carer in the event of a crisis.

- To review the effectiveness of interventions to crisis periods (both short term/long term). This may include but is not limited to, quantitative feedback and opinions provided by service users, their carers and/or professionals before, during or after a crisis, any reference to any impacts interventions may have had on the mental wellbeing of patients e.g. reported management, reduction or increase in anxiety, depression and social engagement of service users, any reference to any changes in physical health, any reference to financial implications including any financial implication to the service user, their carer or family or the commissioning body/care provider.

- The identification of existing preventative services, infrastructure, funding, policies and/or interventions (both short term/long term) within the UK to support individuals with LD who are cared for by an unpaid ageing carer in the event of a possible future crisis.

- To review the effectiveness of preventative interventions in the event of a future crisis. This may include, quantitative feedback and opinions provided by service users, their carers and/or professionals, any reference to any impact preventative interventions may have had on the mental wellbeing of patients before, during or after a crisis e.g. reported management, reduction or increase in anxiety, depression and social engagement of service users, any reference to any changes in physical health, any reference to financial implications including any financial implication to the service user, their carer or family or the commissioning body/care provider.

-To review any instances in which crisis intervention is not available and the impact of this on individuals with LD and their ageing carers. This may include, quantitative feedback and opinions provided by service users, their carers and/or professionals, any reference to any impacts interventions may have had on the mental wellbeing of patients e.g. reported management, reduction or increase in anxiety, depression and social engagement of service users, any reference to any changes in physical health, any reference to financial implications including any financial implication to the service user, their carer or family or the commissioning body/care provider.

- To compare the previously identified financial and psychological outcomes of crisis interventions, preventative crisis interventions and no interventions for individuals with LD within the UK who are cared for by an ageing carer.

*Further criteria will be set in the advanced search terms to include all adults.

Search terms

a. Line 1: carer* OR caregiver OR care-giver OR "care giver" OR care-provider OR "care provider"

AND

b. Line 2: UK OR United Kingdom OR England OR Wales OR Scotland OR Northern Ireland

AND

c. Line 3: aging OR ageing OR older OR old

AND

d. Line 4: intellectual disabilit* OR learning disabilit*

AND

e. Line 5: crisis* OR crises* OR transition OR "crisis intervention" OR "future planning" OR "future" OR forecasting OR "permanency" OR "out-of-home" OR "end-of-life" OR "advance care planning" OR "post-paternal"

*The asterisk indicates that all terms beginning with this root will be searched.