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Adult siblings of people with a learning disability – future plans and concerns

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Title: Adult siblings of people with a learning disability – future plans and concerns

Background

Acknowledgement exists at governmental and societal level of the important role that many family members have in the care of LD people. When parents die, a sibling is often considered next of kin with the expectation of providing support.

Methods

Following ethical approval 1:1 semi-structured interviews were conducted with 15 adult siblings of learning disabled people. Interviews were audio-taped and questions related to the impact of growing up in a LD family and expectations for future care.

All interviews were transcribed and analysed using an approach aligned to Interpretive Phenomenological Analysis

Results

Overall there is a lack of formal futures planning. Some families have a verbal understanding of future expectation, others avoid open discussion but have clear expectations and in others the topic is closed. Reasons for non- discussion include fear, parental attitude, superstition, arguments and stress.

Generally siblings expect to support the LD person in the future but plans lack detail although most parental and sibling future wishes are similar.

Key sibling concerns for the future included service provision, demands upon their time, lack of information, bereavement, their own health and that of the LD person.

Conclusion

The results demonstrate an overall lack of formal futures plans yet diversity within family expectations. Reasons given for a lack of plans include personality traits, life stage, family assumptions and lack of knowledge. Existing plans tend to be informal and transitional in nature. Siblings expect to increase support over time and their expectations often mirror those of parents. Most siblings report future concerns.

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