A Service Response to Supporting Ageing

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What is contained in the report?

- Background
- Models of care
- Person-centred care
- Supporting ageing in place
- Staff training
- End of life care
- Future developments

Background – Why was the report developed?

- Figures from the NIID (2005) show that in Ireland the number of people with ID over 55 years of age has almost doubled from 1974 to 2005 (2010 figures show upward trend continuing).

- For people with ID 'old-age' is generally considered to begin from age 50 years of age (Hatzidimitriadou and Milne, 2005). For people with Down Syndrome there is an increased risk of dementia over the age of 35 (British Psychological Society and Royal College of Psychiatrist 2009)

- According to the Database there are 97 people availing of a service from KPFA in the 'old-age' category.

Fail to plan- plan to fail

It is evident from the figures that planning for ageing is a significant issue for KPFA now and into the future.

As a response to this the committee on ageing was formed and agreed the following terms of reference:

Terms of Reference

- To examine the age and geographic profile of people we support in order to make projections and plan for changing need due to ageing.
- Identify the types and range of supports that are necessary to enable the people we support to live in their own homes as they age.
- To review whether some people we support that are currently in Glebe Lodge (high support house) have a service which is greater than their current need, and who could be appropriately accommodated in a setting with lower supports.
- Quantify the skills and expertise on ageing that currently exist within our staff team. Make recommendations on how these can be utilised to maximum effect for the benefit of the people we support.

Terms of Reference

- To prioritise training in the areas where skill shortages are identified and to recommend how best such training could be provided.
- To identify models and elements of good practice in the area of ageing across our sector and to make recommendations for the introduction of best practice models into existing and future services

The Report

The report is the culmination of the work carried out by the committee. It describes what was found in terms of current best practice models in relation to ageing with ID. It gives an account of the current practices in KPFA and identifies challenges in adhering to best practice. Finally, it sets out recommendations for future service development and identifies how we can achieve our goals.

Models of Care

Going forward supporting those who are ageing will occur in the context of an agreed plan and specific goals as follows:

- Glebe Lodge will support residents with high support needs through to end of life.
- A new facility will be built in Rathmore and will be based on the Glebe Lodge model – it will be staffed and adapted to support those with higher needs and will aim to provide care through to end of life.
- KPFA community houses will be adapted as appropriate to allow those with declining functional abilities to remain in their homes.
- If the support needs of an individual cannot be met within their existing home, transfer to one of the Associations high support houses will occur.

Models of Care

- Use of resources external to the service will be considered to assist in maintaining a person with increasing support needs in their own home.
- Every effort will be made to access generic services available to those without ID who are ageing. Access to SLT, OT, palliative care, pastoral care, should be sought via the normal referral routes.
- Consideration will be given to the development of a specialized gerontology team to comprise of KPFA staff with specific training and experience in ageing.

Person Centred Care

- The person remains within the ID service provision so that he/she can continue to benefit from the more specialized and quality service which upholds the ideals of independence and normalization.
- Care planning and assessment will be undertaken using person-centred approaches i.e. commitment to healthy, active , choice-based ageing.
- Person centred planning reviews will take account of current and future age related needs.

Person Centred Care

- Develop and maintain close working relationships with families and carers in the home who may wish to continue caring but require support to do so.
- Person centred planning must be comprehensive and as such input from non ID services such as GP, PHN, gerontology specialists, physio, OT and community welfare officer, may all be considered.
- Plan for appropriate day and respite care as engagement in meaningful and pleasurable activities is critical to physical and psychological health and well-being.

Supporting Ageing in Place

- A care plan will be in place for all older adults and each plan will be reviewed regularly and modified as appropriate in accordance with changing need.
- Reliance on generic service supports will continue and will be accessed in a timely way so that people are adequately supported to allow for optimal functioning in the least restrictive environment.
- Attention will be given to exploring ways that full assessment needs can be undertaken for those 35+ with Down syndrome and from 50+ for those with ID of other aetiologies.

Staff Training

- Staff training must take account of service provision for the older person with an intellectual disability in health and illness as not all older people we support will necessarily move from independence to reliance.

- Developing a highly trained core team of staff, that would drive practice in elder care may be a cost effective way of training. Part of the remit for this team would be to provide advice, support and education to staff and families in areas where the older person we support is ageing in place.

Recommendations on Training

- Keep a register of training and educational courses that staff undertake.
- Provide information on relevant training/courses available to staff.
- Staff who are funded and/or given time to avail of courses must commit to sharing skills and knowledge with other staff.
- Review staff training every 6 months with a focus on relevance to practice.

Prioritising Training

- ***POMS*** – focus on developing staff skills so that they are better able to support the older person with ID in actualising their goals –(the aim is to grow and develop, not decline).

- ***Supporting People with Intellectual Disability who are Ageing*** – will be part of core training going forward.

- ***Advocacy training*** – being sourced through the Kerry Network of People with Disabilities.

- ***Gerontology nursing-*** Professional development to CNS in Older Persons with ID is desirable

Prioritising Training

- ***Palliative Care*** – currently we depend on the Home Care teams. It would be beneficial to have KPFA staff trained in all aspects of palliative care – could be part of a gerontology team.

- ***Pain Management*** – training is vital to provide quality end of life care. Physicians are hesitant to prescribe for persons who cannot verbalise their pain (Botsforde King 2005). Staff training in the use of an assessment tool to evaluate pain in an objective way would be beneficial.

- ***Bereavement Support*** – Supporting People with ID who are Ageing (core training); IHA Workshops; Seasons for Growth; Clinical Psychologist; EAP (VHI); Bibliotherapy.

End of Life Care

- End of life is best described as a continuum, rather than a point in time (NCAOP,2008).
- The main aim of end of life care for older adults with a prolonged trajectory of decline is adapting the ethos of palliative care.
- Palliative care as defined by the WHO (2002) is as follows:

  "The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of physical, social and spiritual support…The goal of palliative care is achievement of the best quality of life…..many aspects of palliative care are applicable earlier in the course of illness".

End of Life Care

- The philosophy and practice of a palliative care approach has to be adapted in long term care to ensure best practice at end of life that is protective and respectful of a resident's integrity and individuality.
- In relation to end of life care the recommendation of HIQA (2008) is that each resident receives care which meets individual physical, emotional, social and spiritual needs and respects dignity and autonomy.
- Within KPFA, through ongoing experience and in house and external training, a body of expertise in palliative care is developing and growing.

End of Life Care

Glebe Lodge have now commenced end of life planning meetings with families which are proving very valuable for all involved. Families are welcoming the opportunity to talk and to plan. Staff report that families are generally relieved to know that their relative can be appropriately cared for in Glebe Lodge through to end of life.

Also in Glebe Lodge, palliative care is no longer viewed as care offered in the last months/weeks of life. A palliative approach to care can happen over a period of years and we must plan accordingly.

Towards a better response to ageing with intellectual disability

- KPFA, as a learning organisation, is embracing the challenge of supporting people with lifelong ID that are ageing as an opportunity to grow in knowledge and ideas. But, gaps in empirical knowledge limit our ability to reliably advocate for a broader range of intellectual disability specific supports for ageing. It is widely acknowledged that good information on how people with ID experience ageing simply does not exist. One response to this has been the development of the IDS to TILDA study and KPFA are participating in this project.

- But, there is need for additional research in terms of exploring experiences, knowledge and understanding of ageing amongst people with ID that are now in their elder years.
- As an outcome of this report the Association will facilitate the carrying out of qualitative research aimed at exploring this issue.
- This initiative builds on precedent within the organisation where service user consultation has been integral to service development.
- The aim of the study will be to develop a theory of ageing with lifelong intellectual disability and to disseminate the information to the wider service support system.

Thank you for listening.

Any questions?