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Christine Barretto

Catherine Byrne

Mairead Delaney

Aine Harrington

Kira Kazokova

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Supports for parents of children with an intellectual disability: The social care worker's view

Christine Barretto, Catherine Byrne, Mairead Delaney, Áine Harrington and Kira Kazakova

The aim of this research was to explore how social care workers view their role in providing support to parents of children or adults with an Intellectual Disability. The data was collected using semi-structured individual interviews with two practising Social Care Workers with experience working in Intellectual Disability Services, who were part of the research team. It was found that Social Care Workers view themselves as having a role in supporting parents with a child or adult with ID, even where the primary service user engaged with their organisation, was the child or adult with ID. However, while this was identified by the interviewees as being a crucial element of their role it was not always defined as being part of their role or job description within their organisation.

Introduction

In most cases it will be the family, and in particular parents, who will provide the majority of care needs throughout the life of the individual with an intellectual disability. Some research indicates that parents who have limited supports are more likely to experience negative effects, such as emotional and behavioural problems, in response to the stress of providing care for a child with an intellectual disability (Killic, Gencdogan, Bag & Arican, 2013). Hastings and Lloyd (2007) point out that parents who engaged in negative 'expressed emotion' such as high criticality was as a direct consequence of having a child with an intellectual disability. In turn this criticality was found to have a direct impact on the child's psychological well-being. This becomes a more prevalent issue as parents' age (Martins & Couto, 2014). This highlights the importance of understanding the experiences of parents with a child with an intellectual disability and how supports can improve the quality of life for both them and their child.

Leonard (2013, as cited in Whiting, 2013) found that the approach with which parents were informed of a child's diagnosis had long term implications for the parent/child interactions. He also found that parents' perception of this experience was largely negative. Further to this, the perceived negative experience of parents, related directly to the negative perception held by the medical profession of the diagnosis itself. This was reinforced subsequently by future interactions and involvement with other health care professionals.

Some research highlights that parents' concerns were not heard by professionals and it was a challenge to get a diagnosis in the first place (Whiting, 2013). In addition the diagnosis is the start of what Whiting (2014) refers to as a 'battleground' for accessing a resource or service for their child.

The lack of information, accessibility and availability of services or the lack of available services have been found to cause of stress and anxiety for parents (Kilic et al., 2013; Whiting, 2014). The unavailability of supports in early childhood results in parents taking on both educational and caring roles which increase stress, anxiety and depression (Kilic et al., 2013). This has implications for a variety of social, financial and emotional aspects of the parents' and families' lives (Caples & Sweeney, 2010; Souza & Boemer, 2003 as cited in Martins & Couto, 2014). Often parents, specifically the mother gave up a career or a job to provide this care to their child. This exacerbates social isolation, a common issue faced by parent with a child with intellectual disability (Kilic et al., 2013; Martins, 2014). In addition isolation is also increased by friends and families distancing themselves from the parents (Kilic et al., 2013).

The behaviour of the child with an intellectual disability has also been reported to contribute to social isolation. Caples and Sweeney (2010, p.69) report that parents withdraw from social situations with their child as a result of behaviours that challenge and/or behaviours that are socially unacceptable. Parents stated that they "would not go out in public" as it was "less hassle to stay at home". While parents indicated that they engaged in social and leisure activities with their child these were often on a one-to-one basis and socially exclusionary, for example swimming, walking, or going to the cinema. Parents' opportunities to engage in social activities with their child with intellectual disability were limited. Where parents did report positive leisure or recreational activities these were largely through community involvement (Caples & Sweeney, 2010).

Supports and interventions enhancing parents' quality of life identified by research include behavioural intervention, taught positive coping skills, management of expressed emotion, access to social supports and knowledge and education about the diagnosis (Kilic et al., 2013; Hastings et al., 2014). Kilic et al., (2013) argue that a lack of support or the absence of safe communication with professionals is the most significant limitation for families in developing positive coping skills. They also report a relationship between anxiety levels and social support demonstrating that anxiety is reduced by both education and support. They argue that professional health care workers need to enhance their own knowledge in order to offer appropriate supports to parents. Due to the central role of professionals in alleviating

stress and supporting parents this study explores how social care workers view their role in providing support to parents of children or adults with intellectual disability.

Design

This research is small scale and exploratory and therefore a qualitative approach was taken.

Participants

The sample consisted of two practising social care workers who worked the area of intellectual disability with two different organisations. The participants were also part of the research team who conducted the research

Data collection and data analysis

The data was collected using a semi-structured interview. A voice recorder was used to record the interview. Each participant was interviewed separately by two other members of the research team. The recordings were then transcribed and coded in relation to the research question. Each interview transcript was analysed by interviewers separately and then combined to look for similarities in themes/codes across the data.

Ethical considerations

As the participants were part of the research team they were aware of the aim of the study and their role in it. They volunteered their participation because of their practice experience and were directly involved in generating the data collection questions. The interviewees were informed of their right to confidentiality and anonymity and that this may be impacted on by publication of the report. Participants were given the choice not to be named as authors also. The right to withdraw and to refuse to answer any question during the interview was also discussed.

Findings

Need and type of support

Support for parents was identified by both interviewees as a basic requirement for parents. Support was seen as being either informal, for example “an ear to listen to when parents ring to have a chat”, or provided in a more formal and structured way.

[...] supports within the home, parenting [programmes], family support or educational [support] such as workshops.

Both interviewees identified their role in providing information on a range of issues such as nutrition, exercise and access to other services:

[...] educating about the best way to cope with aspects of child’s behaviour, redirecting those in community care to go through GP services (referral routes)...also educating parents that they are entitled too, the sort of things they are entitled too but have to go through their GP, but that they were always entitled to.

The interviewees spoke about the support services that they and their organisations provided. For example, one interviewee worked in a residential community based house that provided care to adults with ID during the week. However, respite services were available to parents in emergency circumstances.

For the other interviewee, providing skills based programmes, home based and clinic based parenting [programmes] and “direction and support about general day to day routines and structures at home” was seen as part of her role.

Support to empower

Other aspects of support provided to parents appeared to aim to empower them. For example, through encouraging them “to follow through on programmes at home, enabling them to be independent and assertive as a parent”. Empowering parents was particularly important as participants reported a tendency for the social care worker to be viewed as being more capable:

Parents presume that we would be better doing that than they are...you’re the professional taking over, your good at everything...a jack of all trades.

Interpreting the language used by other professionals was mentioned by one participant as being part of the support needed and provided to parents:

[...] providing a link to parents to enable them to understand professional programmes and jargon, especially where the information is overwhelming.

This is particularly significant as participants also said that those who had a medical background were less likely to view supporting parents as being part of their role.

Identification of support needs and communication

Not only did social care workers view themselves as an important source of support but one interviewee stated that it was the responsibility of a social care worker to “identify if a parent was struggling”. The example was given of an “added burden if a spouse was in care [nursing home] [...] any way that we can alleviate that [...] by providing extra help when the person [adult with ID] was at home”.

The involvement of parents in the service was seen as benefiting both the social care workers and parents:

I’m very lucky, parents are very involved, good communication links and [parents] are quite comfortable in discussing any issues, and if unhappy with anything happening in our care, will express it and we address it as best we can.

Also both participants spoke about the importance of the relationship they developed with a parent as being fundamental to knowing what support was needed and could be provided:

[...] have to adapt to each person you’re dealing with, need to develop a relationship with parents...intrinsic part of what we do, develop a relationship that you are both comfortable with.

Additional support

The participants spoke about two situations where support or additional support for parents could be required: older parents and dual diagnosis.

Older parents: One interviewee worked within a service where ageing of a parent had presented new challenges. The interviewee described how older parents of her service users had limited to no experience with new technology which acted as a barrier to them accessing information and/or services. The challenges for an older parent was compounded by:

[...] so for instance they might, one or the other might have gone into a nursing home, one is still delivering all the care, so it falls to the one parent. That's an awful lot for one parent to be doing in their seventies and eighties.

Ageing parents...their capabilities of providing the care they used to probably isn't the same.

Dual diagnosis: A significant issue reported by one interviewee was the lack of coordination between services where a child or adult had a dual diagnosis where they “fall between services” and if there was no support to link the parent with services. The interviewee suggested that parents are sometimes overwhelmed in understanding how to access services or know what is available to them.

Support – Who is responsible?

Interviewees reported that the responsibility to support a parent was often the decision of individual social care workers and not a stated organisational responsibility. It was stated that the role of a social care worker in supporting parents of a child or adult with ID with whom they worked was not in their job description. This resulted in the motivation to support a parent being a personal decision on the part of a social care worker:

By not supporting a parent, a vital part, link, is missing for the parent.

One interviewee described the challenge of not having a defined role in their work environment for social care workers and needing “to define our own role”.

[...] a lot of people stick to job description now. A lot to do. Not a lot of support for staffing levels, on my own most of the time. Cooking, cleaning, taking personal care, reports...a lot of people aren't seeing as part of the job to support parents.

I think the new generation of social care workers who have been formally educated and are concerned with seeing it more their role as a holistic things [...] if the floor is not clean, so what.

As interviewees identified that support for parents of a child or adult with ID was not part of their job description, consequently it was not recognised by their organisation as being equal in value to other tasks and training in providing parental support was not given.

[...] not seen as part of job...not recognised or motivated by employer (to support parents)...it is in standards (Organisational Mission Statement)...employers would have a problem...if a complaint was made [...] don't recognise the effort.

One interviewee identified that it was the responsibility of social care workers to educate and upskill themselves in order to meet the needs of services users and family members. It was recognised that this should be supported by employers. The interviewee identified that continuing professional development was provided at the minimum statutory requirements, for example “...health and safety and medical training is in-house”. However “anything outside of this is not provided”.

Needs of the social care worker to enable the provision of support

Interviewees identified a range of continuing professional development supports to enhance social care workers ability to engage and develop positive relationships with parents of a child or adult with whom they worked. Access to training courses was identified as being important such as training on “how to talk to people without putting up barriers or offending people”. Other supports required included regular supervision, peer support groups and learning from multi-disciplinary team meetings.

Conclusion and recommendations

The main findings from this research are that Social Care Workers identified that parents of children or adults with ID required support, both formal and informal, as well as advice and information about how to access services and understanding the diagnosis. Other research found that the absence of support to parents of children with ID results in negative experiences for both parents and their children. Thus the provision of such support can improve the quality of life for both the child and their parent (Kilic et al., 2013). Since the findings from this research clearly suggest areas in which social care workers have identified and provided support the importance of formally recognising the role of a Social Care Worker in supporting parents of a child or adult with ID is recommended.

This research suggests that social care workers, since they are in contact with parents and build relationships with them are ideally placed to provide a range of supports. The lack of information, accessibility and availability of services can cause stress and anxiety for parents (Kilic et. al. 2013; Whiting et. al. 2014) and social care workers are in a position to help with information, access, interpreting professional jargon and empowering parents. In addition the direct provision of services and knowledge of how to access these services is an important factor in supporting parents with a child or adult with ID.

Other findings highlight the specific needs of some parents with a child or adult with ID. This indicates that different sub-groups of parents with a child or adult with ID, have differing needs which should be acknowledged and addressed when planning or providing supports to those parents. For example, the experience of an ageing parent who may be struggling with the physical capacity to care for their adult child may differ significantly from a parent who is trying to access or find services for a child with dual diagnosis. The challenges in finding an appropriate support services was described by Whiting (2014) as a 'battleground' and highlights the challenges which exist for many families. A social care worker in acting as an information source, a knowledge base for directing parents towards their entitlements and acting as a link to accessing support services can smooth the way for parents who may be overwhelmed by the situation.

Furthermore this research demonstrates that challenges exist for social care workers where organisational motivation and recognition of the value of engaging with parents of services users in enhancing the quality of life for all family members is not intrinsic within the job description or the role of the individual social care worker. Kilic et al. (2013) argued the importance of health care professionals, enhancing their own knowledge in order to offer appropriate supports. The importance of the role social care workers play, needs to be recognised and valued through the provision of continuing professional development opportunities for social care workers to engage with, support and enhance the quality of life for parents of a child or adult with ID.

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