Minstead Trust Literature Review Report

Summary

Minstead Trust provides a range of service and activities for people with intellectual disabilities.

Minstead Trust commissioned this review of academic literature. Minstead Trust wished to better understand the ways in which relationships between parents and Minstead Trust staff could be enhanced. While Minstead Trust felt it was working extremely hard to meet parents' needs and was committing significant amounts of unfunded staffing to working on these relationships, they were aware there were differences between parental expectations and the operational deliverable outcomes which the Trust could feasibly provide. Minstead Trust therefore wanted to find out whether recent research suggested this was an isolated phenomenon and if not, whether research suggested any possible trends and solutions.

A review of academic literature was undertaken. Results are presented and solutions from academic literature are reported. Findings suggest this is a global phenomenon and that parents themselves also want to work closely with services. Parents themselves report a range of practical solutions.

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Introduction

Minstead Trust provides training and support that improves the lives of people with learning disabilities. This includes support services that help people to live in their own homes and to learn new skills in day opportunities. Minstead Trust also run employability programmes that support people to learn work skills and gain work experience that can lead to paid work.

Minstead Trust Vision**:** A society where people with learning disabilities enjoy fulfilling lives of their own choosing.

Minstead Trust Mission: We support people with learning disabilities to fully develop their individual potential by providing opportunities, enhancing life skills, ensuring informed choice, and influencing society.

This brief literature review was commissioned to better understand the ways in which relationships between parents and Minstead Trust staff could be enhanced. While Minstead Trust felt it was working extremely hard to meet parents' needs and was committing significant amounts of unfunded staff time to working on these relationships, they were aware there were differences between parental expectations and the operational deliverable outcomes which the Trust could feasibly provide. Minstead Trust therefore wanted to find out whether recent research suggested this was an isolated phenomenon and if not, whether research suggested any possible trends and solutions.

A review of academic literature was undertaken. Results are presented and solutions from academic literature are reported. Findings suggest this is a global phenomenon and that parents themselves also want to work more closely and in partnership with services. Parents themselves report a range of practical solutions.

This brief literature review report includes the method used, the results of the review, a discussion and conclusion.

Method

OneSearch Ex-Libris Discovery was used to search a range of appropriate databases to which University of Winchester has access.

Several searches were undertaken during June 2023 using the following search terms:

- Parent

- Service

- Intellectual

- Intellectual disability services

- England

- Adult

Search parameters were added:

- Available online

- Peer-reviewed journals

- Academic Articles

- Date range 2000-2023

- Written in English

Seven hundred and thirty-eight articles were found and reviewed. Although Minstead Trust supports adults, the topic of transition from child to adult services was found to be important to parents in many of the articles so findings from that literature are also included in the review.

Analysis

Thematic Analysis (Braun and Clarke, 2022) was chosen as the most appropriate analysis method. Braun and Clarke's six-step analysis was used to discover codes, which were then used to create themes.

Results

Four key themes from the academic literature were created. These were: the ways in which the social care system was considered to be unfit for purpose; Parents and stress; Relationships with service providers; and Possible solutions. These are presented below:

Theme One: The social care system was considered to be unfit for purpose.

The literature overwhelmingly found that parents were surprised, angry and disappointed that the system of adult social care for their son/daughter was so significantly underfunded. Parents described their disappointment at finding they had to 'fight' for every service they had gained for their son/daughter. It was this approach that many parents found themselves having to take in all their dealings with professionals and services when their son/daughter was a child. Some parents expected that services would improve as their child entered adult services. Many were surprised at how underfunded, disorganised, complex, inconsistent and uncoordinated the adult services system was. Navigating this system was described as confusing and exhausting. Parents described themselves as "having to" advocate for their son/daughter as no-one within 'the system' appeared to have their son/daughter's wishes at heart.

Parents accessing adult care services for their son/daughter reported this often happened in an unplanned way, either because of a family crisis or their son/daughter 'ageing out' of children's services with parents having no understanding or information regarding next steps.

Many parents reported having no faith that 'the system' had the ability to meet the needs of their son/daughter.

Parents reported feeling that changes to the current system, or a new system would be brought in without notice, which would mean their son/daughter would be moved to a new service and forgotten about.

Theme Two: Parents and stress.

Parents were described in the academic literature as being under intense stress. This appeared to be linked to intrinsic and extrinsic factors. Intrinsic factors included the level of need their son/daughter had; higher levels of need (including behaviours that challenge, severity of disability and verbal ability) equated to higher levels of parental stress. Extrinsic factors which negatively impacted on parental stress levels included lack of family support, lack of social support and lack of systemic support. These factors then reduced parental quality of life and negatively impacted on the quality of life of their son/daughter with intellectual disabilities. Stress was linked to poor parental psychological wellbeing. Stressed parents were less likely to take part in social activities and were more likely to report being depressed.

Higher levels of stress were linked in the literature to greater unwillingness of parents to 'let go' of their son/daughter, and greater levels of unwillingness to place sons/daughters in day services or residential care.

Stress was also reported as being related to fear for and of the future. Parents described stress levels being negatively impacted by services primarily in terms of lack of information about the processes involved in transitions. Transitions were described as frightening, and parents often felt scared about what the future held for their son/daughter. Parents were keenly aware that when they died, there would be no-one caring and advocating for their son/daughter. Many feared their son/daughter would then be abused and without help.

Parental stress was linked to a feeling of having no control over one's situation, environment or experiences and of feeling unvalued.

Theme Three: Relationships with service providers.

The literature review also found that:

Service providers were reported to have been expected by some parents to alleviate their stress and offer support. Instead, parents reported services caused stress and significant amounts of additional work for parents. Parents who did not get information regarding the process of getting a service were, in some studies, related to parents experiencing higher rates of stress when their son/daughter did get a service.

Studies reported parents felt the need to "scream loudly" in order to be heard by services and to get a satisfactory service for their son/daughter. Parents were aware of the difficulties this "advocating aggressively" caused in their relationships with professionals, but many felt they had no other option open to them.

Parents often experienced services as 'cold', 'insensitive', 'distant', 'detached' and 'lacking empathy'.

Some parents felt 'lucky' when they found a key person who knew and cared about their son/daughter, finding such a person was considered to be a rare event which was usually short-lived (typically because that staff member moved away from that role or service). Some parents described this type of professional as their only form of support. It was felt that this person could provide much needed continuity.

Providing services to sons/daughters without supporting parents was considered to be a sure way to create crisis, increase anxiety and increase unnecessary service provider spending.

Parents found agencies and organisations working in silos created further burdens and difficulties and highlighted the polarities between service providers and parents. Some parents felt there was no collaboration at all between agencies, and this also caused them difficulties.

Parents often referred to 'they' when talking about a range of agencies and service providers, and described feeling there was a significant gulf in understanding and expectation between parents and service providers.

Parents reported that secure relationships with services were strongly associated with their needs for help, advice and support being met. Parents in these relationships felt they did not need to "scream loudly" for help as they felt listened to and supported.

Some parents felt aggrieved that their son/daughter's services were not effectively funded. Others felt that services appeared to be undertaking significant fundraising so wondered why their son/daughter's service had not improved. Others whose son/daughter had benefitted from fundraising activities felt lucky that this had been the case.

Theme Four: Possible solutions.

The literature suggested that:

Parents wanted meaningful, supportive, collaborative, strong and secure relationships with service providers where parents were seen, heard and treated as important people who were understood to be part of a family unit.

Some parents were so stressed they wanted someone else to 'take over' and deal with the many different and disparate parts of 'the system' and advocate for their son/daughter on their behalf.

The literature found that parents wanted access to services and information about services to be simplified.

Parents felt regular evaluations of services should take place which elicit the opinions and voices of parents.

Support programmes specifically for parents were reported in the literature as being felt by parents to be vital for their wellbeing. They felt these programmes should support parents to have an active

social life and promote resilience. Parents reported they felt programmes should aim to enable parents to reduce their stress levels and manage fearful and depressive feelings. Parents felt support programmes should bring together parents in similar situations.

Early intervention by services in terms of long-term future planning was considered to be helpful in supporting parents to 'let go'. Parents felt services should help parents plan for the long-term future care of their son/daughter and how they would manage their own and their son/daughter's ageing process. One-to-one guidance and support were felt by parents to be important in helping them to manage their fear about the future; parents wanted a personal touch, 'special help', advice and support.

Parents wanted service providers to see the family as a unit and to work with families in a collaborative manner, in accordance with each individual family's wishes, strengths and needs.

A knowledgeable and person-centred connector /co-ordinator who worked collaboratively and kept in regular verbal contact was considered by parents to be important. This 'key person' could oversee transitions, provide information and keep in touch with parents regularly, involving them in decisions about their son/daughter.

Parents felt written information should be provided in a timely manner by services and be in an accessible format. It should outline options for current and future provision. This information should also include the housing and support priorities of the service provider.

Treating each individual parent and person with intellectual disabilities as an individual with particular needs and wishes was considered important.

Service providers working in partnership with other organisations and agencies was considered to be important.

Discussion

It is important to note that issues of parental expectation not matching deliverable outcomes by the services supporting their sons/daughters is reported globally in the academic literature. This is not a phenomenon unique to Minstead Trust or indeed to the U.K.. Systems which it was felt should support people with intellectual disabilities and their parents were often reported to be failing in this regard across all countries in which research was undertaken. These issues are reported across countries in Europe where traditionally high levels of satisfaction have been reported since ground-breaking new ways of understanding the concept of intellectual disabilities were introduced in the 1970s, and in countries in the Global South which research demonstrates also have a range of different and often innovative ways of supporting people with intellectual disabilities and their families.

Parents feeling they must fight against systems and services has been reported in the academic literature for decades. Similarly, parents reporting they would like to be far more involved in their son/daughter's care has been reported by parents for many years.

It may be that before parents have any dealings at all with Minstead Trust that they have already felt the need to fight in ceaseless battles with a range of services to get even a minimum amount of care for themselves and/or their son/daughter. The literature suggests parents find this a waste of their time and energy and would prefer to work in collaborative ways. They suggest this also is more cost-effective for services.

Some parents then may assume that their relationship with Minstead Trust, as with their many other relationships with professionals, will be characterised by mistrust and that they as parents will have to fight and "scream" to get what they deem to be an appropriate service for their son/daughter. Others may assume that they will get a poor service and feel lucky if this is not the case. Others may

expect a level of service that any adult service funded by a Local Authority simply cannot provide, no matter how much fundraising Minstead Trust undertakes.

Parents of adults living at Minstead Trust or using Minstead Trust services may want support services for themselves to help them to navigate the transition between child and adult services. They may also desire personalised support to help them to plan for their own and their son/daughter's long-term future. They may want services which enable them to achieve an active social life and social network, linked to other parents.

The literature suggests that parents overwhelmingly desire positive, productive, meaningful relationships with professionals. Having an individual that parents know they can trust, who is felt to know their son/daughter well and care about their son/daughter appears to be vitally important to parents. This can of course have emotional and financial consequences for people with intellectual disabilities, parents, individual keyworkers and for Minstead Trust.

Limitations

This review was brief and searched a wide range of databases associated with topics not limited to social care. It included information from a wider range of countries than initially considered. Both these factors may have affected the results produced. Parents typically report a lack of time and energy to take part in research, which may affect the ability of any researchers to reach parents who have less opportunities to give voice to their experiences. There remain though key themes across the included literature which does give validity to claims made regarding the possible wishes of parents and the ways in which these may impact on the situation of Minstead Trust.

Conclusion

Minstead Trust commissioned this brief review of the academic literature to gain a sense of the state of relationships between parents and service providers more widely than their own experiences.

Minstead Trust are keen to work in effective, meaningful and cost-efficient ways with parents and with people with intellectual disabilities with whom they work.

Differences in experience and expectation have been reported between parents, who were keen to highlight their individuality. That said, the literature did also highlight key similarities in experiences. Suggestions from the literature for possible reasons for differences in understanding, and ways of working which may enhance parent-professional relationships have been suggested.

It appears that the desire to work more effectively with parents may be mutual and enhancing this way of working may produce mutually beneficial results for both parents and Minstead Trust.

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