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Respite care for families with children with Autism Spectrum Disorders: how services in Northamptonshire UK are working to meet the challenge

Value and benefits of respite care for families with children with ASD

Respite care services for disabled children – or 'short breaks' as they are now named in the UK – are social care services that enable such children to spend short periods of time (from a few hours to a few days) away from their families. Such services have developed rapidly in the UK since the 1980s (Stalker, 1996) and have been shown to be of benefit to families, the disabled children, and to the state.

Benefits for families

Respite care has long been identified as important for families with children with ASD (Bristol and Schopler, 1983). Families with children with ASD can experience higher levels of stress than those whose children have other impairments (Koegel et al., 1992; White and Hastings, 2004). However, they often have limited social support from relatives, neighbours and friends (Boyd, 2004; Preece and Jordan, 2007a). Respite care can help reduce stress in families (Chan and Sigafoos, 2001), as well as provide them with the chance to have a break from caring and doing things that they cannot do while the child with ASD is at home (Preece, 2000; Tarleton and Macaulay, 2003).

Benefits for children with ASD

Appropriate respite care can also give children with ASD positive experiences (Preece and Jordan, 2007a; Tarleton and Macaulay, 2002). Such services can provide both social and educational opportunities, enabling the children to generalise existing skills and learn new ones, as well as taking steps towards greater independence and adulthood.

Benefits for the state

Effective respite care can also provide benefits to the state. Respite care can help families carry on caring for their child (Beresford, 1994) and can reduce expensive out-of-family placements (Abelson, 1999; Boyd, 2002) and the long term costs to the local government of intervention and support (PricewaterhouseCoopers, 2007). Also, when children with ASD remain living in their local communities, it is easier to plan and develop appropriate services to meet their needs as adults.

Obstacles for effective respite care

However, although respite care can be beneficial on many levels, there are a number of obstacles for families with children with ASD experiencing positive respite care support.

Inappropriate services

Considerable research and literature within the fields of education and psychology identifies that the impact of the characteristic impairments of ASD causes children with this condition to require specific, special types of intervention and education (Ozonoff et al., 2003; Simpson, 2005). Their educational and treatment needs are identified as being different from those of children with other disabilities. Approaches and settings that are appropriate for other children with special needs do not necessarily work for them (Jordan and Jones, 1997) and consequently many children with autism may need to attend a school or unit specific to autism (Jordan et al., 1998).

Research shows that specific, special types of intervention are also needed in social care supports for individuals with ASD and their families – and that generic respite care services for 'disabled' people can be inappropriate for those with ASD (Barson, 1998; Van Bourgondien and Elgar, 1990). Problems can occur for a number of reasons, including lack of staff understanding and expertise about ASD; ecological issues, such as noise, light, space, security and staffing levels within the environment; the types of activities on offer; and as a result of attempting to meet the needs of a wide range of children with differing needs and abilities within the same setting.

Inadequate levels of service availability

About a third of the families on waiting lists for short breaks in the UK have children with ASD (Tarleton and Macaulay, 2002), and many wait for years without ever receiving a service (Barson, 1998; Sargent, 1995). Even where services are available, the level of service available may be too little (Preece, 2000) and demand for services far exceeds availability. Brady (1998) found that 55% of families with children with ASD considered lack of short breaks as a problem.

Eligibility criteria

More able children with ASD – such as those with Asperger Syndrome (AS) – are less likely to access respite care services than those with ASD and additional learning disabilities (Preece and Jordan, 2007a) and may be considered too able to meet eligibility criteria for services (Oberheim, 1996). The behaviour presented by many children with ASD – such as self-injury or smearing faeces – can prevent them from being accepted by some services (Barson, 1998). Moreover, even when children with ASD initially meet eligibility criteria for respite care services, they are often subsequently excluded due to the impact of their behaviour on others (Sargent, 1995; Van Bourgondien and Elgar, 1990).

Understanding and attitudes of social workers

In the UK, families can only access social care services, such as respite care, as a result of referral by a social worker employed by the local authority. At the individual family level, the role of the social worker assessing their situation is crucial. Decisions about whether the family are eligible to receive a service, and what type and level of service should be sought, all depend upon the social worker's assessment.

However, social workers and parents may conceptualise short breaks differently, attaching different values to differing models of service. MacDonald and Callery (2004) suggest that social workers tend to perceive services that remove disabled children from their families (even for short breaks) negatively, and that they seek to provide services that do not remove the child from the family home. Nonetheless, parents still value services that provide them with overnight breaks (MacDonald and Callery 2004; Preece, 2000), while reactions to in-home services are mixed (Olson and Maslin-Prothero 2001).

Preece (2000, 2011) further identifies that parents of children with ASD consider short breaks, where the child leaves the family home to fulfil a number of different functions, including providing a break from caring, providing social opportunities both for the child with ASD and the rest of the family, and fulfilling a social educational role for the child. However, MacDonald and Callery (2004) find that often social workers considered this model of service as their least preferred option, suitable only in crises; and the gate-keeping of scarce services further means that access to short breaks is often restricted to those families whose circumstances are most difficult.

Furthermore, many social workers have an inaccurate understanding of ASD (Preece and Jordan 2007b). This can further militate against families receiving appropriate services, as social workers may underestimate the difficulties facing some families, or misjudge the type of support that they need. All of these factors can prevent families receiving appropriate services, as social workers may underestimate the difficulties facing some families, or misjudge the type of support that they need.

What is needed?

Considering the range of different functions that it may perform, Lindsay (1996) suggests that a spectrum of respite care services is required. These functions include

- *domiciliary* respite care (where support is provided in the family home)
- *holiday* respite care (to allow the disabled child and their family – either together or separately – to have a holiday)
- *emergency* respite care (to address unexpected or emergency situations)
- and, most importantly, *planned* respite care, to provide regular short breaks for the child and family.

Respite care services within Northamptonshire, UK

Respite care services have been developed to meet the full range of respite care needs (Preece, 2003). *Domiciliary* respite care is provided either by contracted agencies or through direct payments made to the families. *Holiday* respite care is provided through a range of methods. These range from signposting families to sources of grant funding to providing direct payments (either to pay for workers to accompany the child on a family holiday or to support the child at home while the rest of the family have a break). *Emergency* respite is provided either by the county's residential respite home (for up to 28 days maximum), with a 'contract carer' or through short-term fostering. Finally, and most crucially, *planned* respite care is provided by family-based and residential services.

Furthermore – and acknowledging the need of individuals with ASD for specialist, autism-specific approaches and services – these respite care services form part of a planned and integrated range of services for people with ASD and their families within Northamptonshire.

Northamptonshire

Northamptonshire is a mainly rural county in the centre of England, about sixty miles north of London. It has a population of about 650,000 – about a third of this population live in Northampton, the county's main town. The county has a school-age population (3 – 18 years) of about 100,000 – about 1,000 of these children have a diagnosis of ASD.

Since 1990, education, health and social care service providers and parents in Northamptonshire have worked together to develop a multi-disciplinary, integrated approach to providing services to people with ASD (Preece et al., 2000). A range of services has been established, including autism-specific educational, day care and work settings, advisory services for schools and families, job coaching for adults, and residential care for adults and children. Services in the county are grounded in the consistent use of the structured teaching strategies of the TEACCH approach (Mesibov et al., 2005). Key facets of this approach are:

- physical structure: clarifying the purpose of physical space, reducing distractions
- schedules: visually presenting information about what will happen and when
- work systems: providing organisational strategies to complete activities
- visual structure: helping with organisation, increasing clarity and providing instruction.

Services also utilise related interventions that complement the TEACCH approach, such as the Picture Exchange Communication System (PECS) (Frost and Bondy, 2002) and Social Stories™ (Gray and Garard, 1993).

Family-based respite care

Prewett (1999) identifies a nationwide shortage of family-based respite care placements for children with ASD in the UK. To address this, Northamptonshire County Council recruited and trained ASD-specific 'contract carers' across the county. Each carer is contracted for 208 days per year (including 24 days paid leave) and is required to provide 182 days of care per year, including 26 weekends, in their home. They look after one child, or sometimes two children, at a time, for which they receive a retaining salary and an additional payment for each overnight stay from the county council – the service is free to families.

The contract carers support up to eight families each and this service has been targeted particularly towards families with younger children, or those who find it hard to cope with group living. Whereas breakdowns are generally high in family-based respite care placements for children with ASD (Sargent, 1995), placement stability with the contract carers has been high (Preece, 2003).

Residential respite care

Residential respite care is provided at a six-bed residential home located in one of the county's towns. This home provides service to forty families with children aged between five and eighteen years, and is open 360 nights per year. Stays are pre-booked, with children staying a maximum of four nights at a time. Each family's package of support is individualised, dependent on factors such as their assessed level of need, the child's age, needs and wishes, and availability. Currently, packages of care vary from 12 to 96 nights per year, with an average of 30–40 nights. Again, services are provided free to families.

Photo 1. The residential respite care home

The professional staff team at the home comprises the registered manager, two senior residential care workers, and four residential care workers. They are supported by night staff, care assistants, a cleaner and a clerk. The staff- child ratio is at minimum 1 member of staff per 2 children. However, more staff will be deployed if this is identified as necessary. During the night, a member of night staff is on duty, with a member of the professional team sleeping-in at the home, and another on call. Each family has an identified 'key worker' from the professional team, who is their main point of contact with the service.

Northamptonshire's respite care services for children with ASD have been externally identified as effective (Social Services Inspectorate/Audit Commission, 1999) and exemplars of good practice (Carlin et al., 2004), and research has indicated a high level of parental satisfaction (Preece, 2002).

Making respite care effective for children with ASD

Making respite care work for families with children with ASD can be challenging, but such services are important tools not only for providing families with effective, dependable and regular breaks, but also to give children with ASD social opportunities and to help develop their independence. Interviews carried out with families who used these services (mothers, fathers, siblings, and the children with ASD themselves) identified a number of factors which the families associate positively with quality services (Preece, 2009). These factors are:

- the physical environment
- staff attributes, including their understanding of ASD
- consistency with other settings and use of ASD-appropriate approaches
- individualisation
- activities on offer
- grouping of children

These factors are discussed below. All quotes are from families using respite care services in Northamptonshire.

Physical environment

The nature and appropriateness of the environment – providing a structured yet homely setting – is of fundamental importance to families.

"I don't know what I was expecting really… just something a bit clinical and institutional, really. And I was so pleased that it was a normal house... It looked like a normal house and that was really nice." (Mother of a child with ASD)

Photo 2. A bedroom in the respite care home

The link carer's homes are 'normal' homes in local communities. Residential respite care is provided at a seven-bedroom detached house in a small town. The physical environments across these settings have been modified to be 'autism-friendly'. Walls are decorated in muted and pastel colours, and rooms are largely free of ornament and clutter to reduce confusion and over-stimulation. Clarity of physical structure is important to children with ASD (Mesibov et al., 2005) and so the different areas of the environments – bedrooms, bathroom, play areas, dining rooms – are clearly identified and labelled.

The residential respite care home has six bedrooms available for children and these are differentiated to address different needs – some have running water, while others do not; some have carpets, others have waterproof floor coverings. Where possible, children sleep in the same bedroom every time they stay at the home. The home has a transition area – where children's TEACCH schedules are located – and two separate gardens – a larger area with play equipment, and a smaller sensory area. The building is externally secure with external doors opened by electronic keypads, and window and door alarms. Other safety and security features of the building include built-in storage, alarms on bedroom doors, flush fitting lighting and toughened glass in all windows.

Photo 3. The home's transition area

Staff attributes, including their understanding of ASD

> The people… they really knew what they were talking about. They seemed to really understand autism… They seemed very willing to chat to you about everything, and would be willing to try anything that would be suitable for your child (Father of a child with ASD).

The skills, attributes and expertise of the workers involved are crucial in making respite care work. Peeters and Jordan (1999) identify a range of personal attributes they consider necessary for workers in the field of ASD – to be ‘bitten by the bug of autism’ and to have imaginative skills, the ability to adapt their natural style of communication and social interaction, the willingness to work as part of a team, adaptability and humility. Many of the workers in the services clearly have been ‘bitten by the bug’, and as a result staff turnover is low, which helps maintain consistency.

Training is also vital. Contract carers and residential care workers are all consistently trained within the TEACCH model. All workers receive initial induction training in ASD and in the use of structured approaches. Within the residential respite care service, all staff attend a 3-day TEACCH seminar; all of the home’s professional staff attend 5-day, intensive hands-on TEACCH workshops, as well as receiving training in Social Stories™ (Gray and Garard, 1993) and PECS (Frost and Bondy, 2002). Workers have also been supported to undertake higher education courses at the University of Northampton and the University of Birmingham.

Consistency of approach across environments

> It is important that there is consistency to keep the continuity between school, home and respite care. If everybody uses the same strategies, the children are less confused (Mother of a child with ASD).

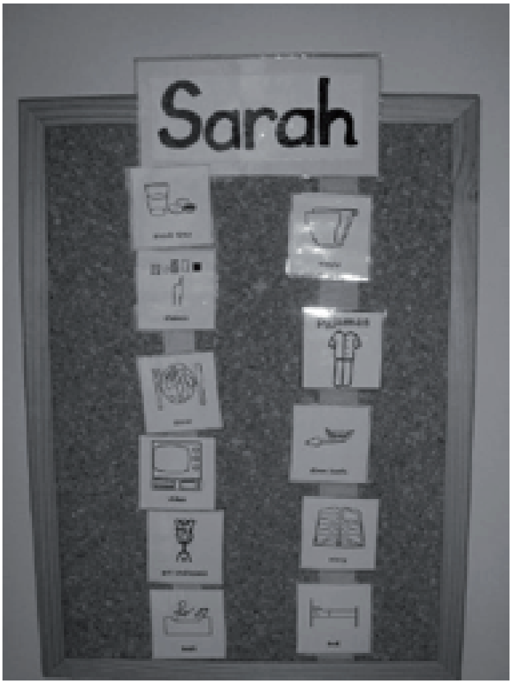

Photo 4. Visual supports are used consistently across environments

Before any respite care stays, the residential staff or contract carers will visit the family home, and observe the child in school, to identify where positive routines have been developed, so that these can be replicated. TEACCH schedules and visual supports will be developed to be consistent with those used at school or in some cases these visual supports will be made more concrete to help the child cope with the new environment. The contract carer or the allocated key worker from the residential respite service will complete an autism-focused assessment with the family to identify the child's physical needs, self care skills, communication skills, social interaction, interests, likes, dislikes, routines and behaviours. Any sensory or perceptual issues that the child might have (Bogdashina, 2003) are also identified.

The contract carer or key worker liaises regularly with the child's family and school to ensure that the systems in place in the respite care setting remain current and appropriate, and that they take account both of the child's development and of any difficulties they may be having.

Individualisation

> They're all individuals, you know. If you have [a] room full of autistic children, they can be completely different from each other (Mother of a child with ASD).

All children using the respite care services are provided with individualised daily schedules (telling them the sequence of events), work systems (to help with tasks such as dressing, washing and toileting), and communication systems. These are differentiated to match each child's communicative level and can range from functional objects to written systems. Daily schedules are, where possible, developed so that the activities the children undertake are built around their strengths and interests.

> Andy, Annette's husband, was into all the cars and that. So he would just sit in garage with him. And she had a PlayStation and that, so he was happy (Sister of a child with ASD).

Within the residential respite home, this level of individualisation means that – at any given time – up to six children, all potentially using schedules and visual supports at different levels of abstraction (from objects to written words) – may be engaging in different activities. The role of the key worker is central to carrying out this individualisation effectively. Key workers are responsible for ensuring that appropriate structure and visual supports are in place, and ensuring that other staff are aware of each child's needs.

Activities are coordinated through the use of the children's individual daily schedules. This requires thorough timetabling and planning by the staff team. The day is divided into three shifts: morning (7 a.m. to 2.30 p.m.); afternoon (2.30 p.m. to 9.30 p.m.) and night (9.30 p.m. to 7 a.m.). Before the start of each shift, workers are identified to take responsibility for children allocated to them. These workers discuss and plan the activities the child will undertake during the shift. The shift is planned as a group, so that group activities are structured, and individual activities are synchronised to avoid clashes.

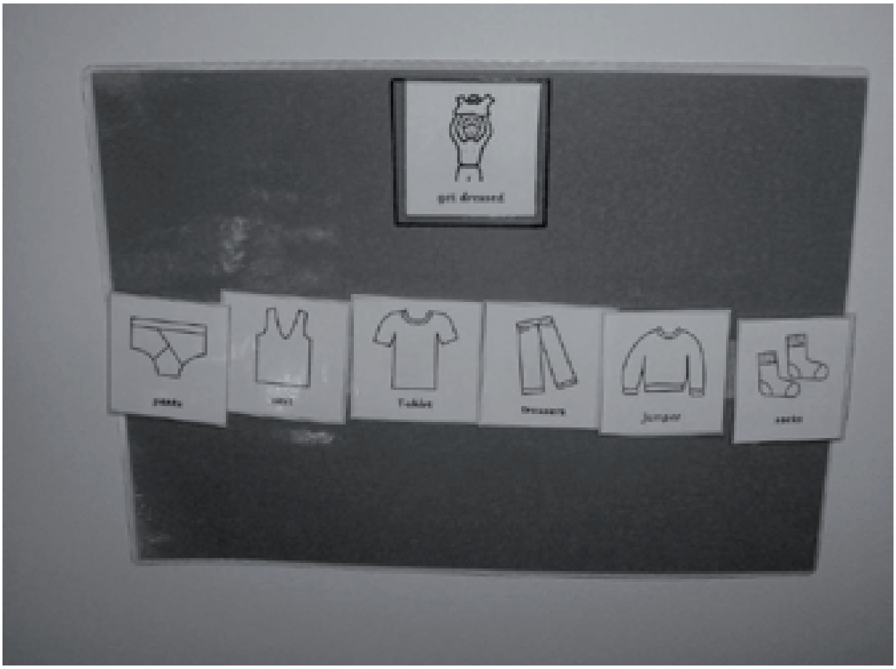

Photo 5. A work system enables a child to dress independently

Use of ASD-appropriate approaches

> Since…using TEACCH he has been able to finish things, accomplish basic tasks, get through the day, understand what's required of him, and his frustration has reduced. I've seen and been through what he's like without TEACCH…the behavioural problems are unbearable (Mother of a child with ASD).
>
> (Schedules are helpful)…'cos then I don't forget what I'm supposed to do (Teenager with ASD).

The use of ASD-appropriate approaches and tools is vital in making respite care work for these children and their families. The TEACCH approach uses structure at four levels – physical structure, daily schedules, work systems, and visual structure (Mesibov et al., 2005) – and these are integral in both contract carer's homes and at the residential respite service. Tools such as choice boards and PECS communication systems, and visual information (such as visual calendars and sleep charts) are vital to help children communicate their preferences and wishes, cope with waiting and sharing, and understand when preferred activities will occur.

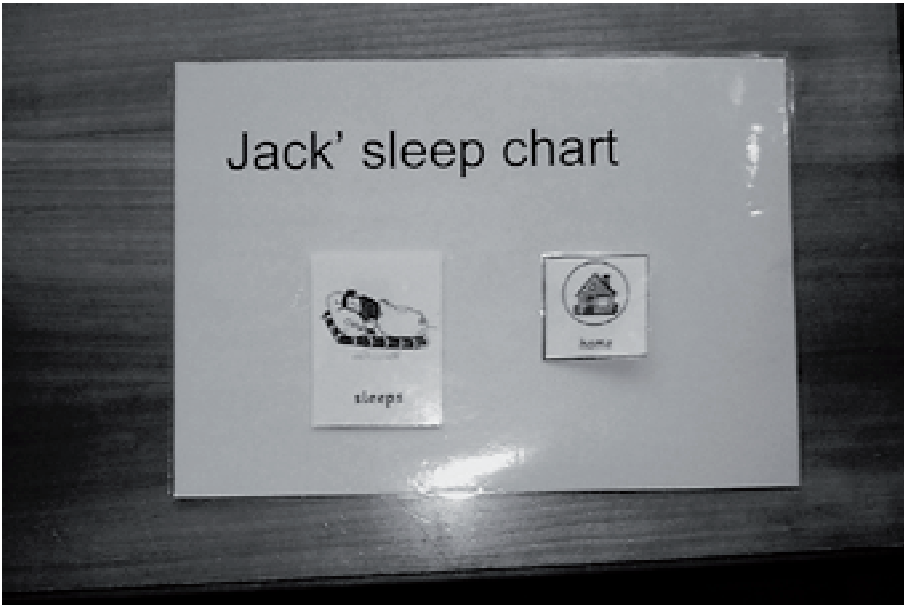

Photo 6. A 'sleep chart' lets a child know when he will return home

Activities

> Annette took me to the cinema. Going to Annette's was fun! (8 year old with ASD).
> The best thing is that… if it's a nice day you get to go out (Teenager with ASD).

Accessing the community, and learning to undertake and enjoy outings and community activities, are important aspects of the respite care experience for children with ASD. Children attending respite care services engage in a wide range of activities, including trips to parks, nature reserves, swimming, museums, cinemas, shopping, restaurants and the seaside. As with other activities, the use of structured approaches and visual supports helps the children understand what is going on, helps reduce confusion and anxiety, and clarifies when activities will end (and what will happen next).

Grouping of children

> I get on really well with him… we just wind each other up and have a laugh (Teenager with ASD).

Generally children staying with contract carers are there alone or perhaps with one other compatible child. When planning respite care at the residential home, it is important to book children's respite care so that they are in the home with children whose behaviours they can tolerate, who share some common interests and skills (so that group activities can be undertaken).

Limitations and problems

Northamptonshire's multidisciplinary approach, and the consistent use of ASD-appropriate strategies, has enabled respite care services to be developed that meet with the approval of families, children with ASD and external assessors. However, significant limitations and difficulties remain.

Demand exceeding capacity

The county's respite care services are running at full capacity. Some families have to wait for several months between being identified as eligible for a service and beginning to access it.

The number of children with a diagnosis of ASD within the county rose from approximately 100 in the early 1990s to over 600 fifteen years later (Whitaker, 2007). The level of service available has not risen in line with this increase, and research (Preece and Jordan, 2007a) has shown significant levels of unmet need. Over half the families who participated in this study expressed a current need for respite care, and almost two thirds felt they would need it in the future – but such services were only being accessed by about a quarter of the families. Unmet need is particularly significant among families whose children with ASD are higher functioning, in mainstream schools or under eleven years old; and in families who do not have a social worker.

Need for different types of service

Families and children have also expressed the desire for a wider range of service models. These include services specifically for children with Asperger Syndrom (AS); services aimed at teenagers; workers who can provide care for all the family's children (not just the child with ASD); after-school clubs; support with children's preferred activities (such as trampolining); and support for siblings.

Availability of funding

While the population of children identified with ASD is growing, services are dependent on the availability of funding from local and central government, and upon the competing demands and pressures from other publicly funded services – the police, emergency services, schools, other areas of social care, and so on. This means that funding is always limited and that budgetary pressures are inevitable.

Conclusion

This paper discusses how one UK local authority has sought to address the issue of providing appropriate respite care to families with children with ASD, within the context of a multi-agency ASD strategy based upon the principles of the TEACCH approach. What has been appropriate in Northamptonshire may be inappropriate elsewhere – both within the UK and elsewhere in the world – and there are undoubtedly many other ways in which services could have been developed. Nonetheless, the "Northamptonshire approach" is offered as an example of what has been done, and it is hoped that this information may be helpful for others.

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Respite care for families with children with Autism Spectrum Disorders: how services in Northamptonshire UK are working to meet the challenge

Abstract

This paper identifies the importance of respite care services for many families with children with autism spectrum disorder (ASD) but also some of the obstacles that may prevent families accessing such services. It describes how Northamptonshire County Council, a local authority in the United Kingdom (UK), is working to meet the challenge of providing 'autism-friendly' respite services. The paper outlines factors that families have identified as being positively associated with quality in respite care for children with autism and their families. These are the physical environment, staff attributes and their understanding of ASD, consistency with other settings, the use of ASD-appropriate approaches, individualisation, the activities on offer, and the way that children are grouped. As well as outlining the major characteristics of these services, and how they seek to meet the needs of families with children with ASD, the paper describes the limitations of these services and the challenges and issues that remain.

Opieka zastępcza dla rodzin z dziećmi z zaburzeniami ze spektrum autyzmu: jak działają służby w Northamptonshire w Wielkiej Brytanii, aby sprostać temu wyzwaniu

Streszczenie

Niniejsza praca przedstawia znaczenie służb opieki zastępczej dla wielu rodzin dzieci z ASD, lecz także identyfikuje przeszkody, które uniemożliwiają rodzinom dostęp do takich usług. Opisuje ona, w jaki sposób rada hrabstwa Northamptonshire, władza samorządowa w Zjednoczonym Królestwie Wielkiej Brytanii i Irlandii Północnej, pracuje nad sprostaniem wyzwaniu zapewnienia „przyjaznych dla autyzmu" usług opieki zastępczej. Niniejsza praca przedstawia w zarysie czynniki, które zostały uznane przez rodziny za pozytywnie kojarzone z jakością opieki zastępczej dla dzieci z autyzmem oraz ich rodzin. Są nimi: środowisko fizyczne, cechy pracowników i ich wiedza o ASD, spójność z pozostałym ośrodkami, stosowanie odpowiedniego podejścia do ASD, indywidualizacja, oferowane zajęcia oraz sposób dzielenia dzieci na grupy. Oprócz zarysowania głównych cech tychże służb oraz tego, w jaki sposób usiłują one sprostać potrzebom rodzin dzieci z ASD, niniejsza praca opisuje także ograniczenia tych służb oraz wyzwania i problemy, przed którymi stoją.

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