Department of Health & Social Care

Research and analysis

A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families

Published 25 February 2021

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This study was conducted by the Chief Social Workers for Adults and the Chief Social Worker for Children and Families.

Applies to: England only

Setting the context

As the Chief Social Workers, we are committed to promoting social work as a key professional contribution to improving the quality of people's lives. We know and understand that strengths and rights-based social work practice, with the person at the centre, can facilitate very significant change.

By drawing in the right resource and expertise as well as offering emotional support and motivational guidance, social workers at their best can offer creative insight to help people maximise their independence, exercise choice, and help coordinate the multiple social inter-dependencies upon which we all rely.

Despite a raft of legislation, regulations, and guidance, we know that public services don't always offer the support that families need, and at the time they most need it. Practice reviews can tell us a lot about what actually happens by looking through the professional's lens but also, in a critical way, through the lens of experience from those receiving services.

Isabelle Trowler, Chief Social Worker for Children and Families

Lyn Romeo, Chief Social Worker for Adults (at time of study)

Mark Harvey and Fran Leddra, Joint-Chief Social Workers for Adults (interim)

The role of social work in the lives of autistic people and their families

Social workers often take the lead role in ensuring that the statutory requirements of the Children Act 1989, Children and Families Act 2014, Autism Act 2009 and the Care Act 2014 are met. In addition, they are often decision makers under the Mental Capacity Act 2005 as well as best interest assessors in relation to Deprivation of Liberty Safeguards (DoLS). They will also have an even wider and pivotal role in the new Liberty Protection Safeguards (LPS) for people who lack capacity to make decisions about their care.

They may also act as Approved Mental Health Professionals (AMHP) under the Mental Health Act 1983, offering an independent oversight of the assessments and determination as to whether someone should be detained under the act. They provide a social care perspective during such assessments, ensuring that the least restrictive options to a person's liberty are pursued.

The approximate numbers of registered social workers in England is:

- 16,000 in adult social care services
- 29,000 in children's social care services
- 2,500 in the National Health Service, primarily in mental health services

Social workers involved in an autistic person's care have a duty to promote their human rights, safety and wellbeing, assess their needs and help facilitate access to the right services. Their role is to:

- ensure that people who need care and support receives that help in a way which enables them to have a voice, stay safe and live fulfilling lives
- promote human rights and inclusion, and embed strengths-based and personalised approaches in practice
- enable choice and autonomy, for example by removing any barriers to participation and by using the least intervention possible to ensure safeguarding
- develop specific knowledge and skills to work with autistic people, and able to manage complex family and group dynamics and facilitate change
- have strong legal literacy and confidence in being the professional voice of challenge and advocacy across systems, and representing the person's best interests always and in all places, is at the core of social work practice

The key pieces of legislation for social workers are:

- The Autism Act 2009 statutory guidance clearly sets out that those assessing autistic people must have the knowledge, skills, competence, and training to carry out assessments
- The Care Act 2014 requires local authorities (LAs) to make sure that any adult, or their carer, who appears to need care and support should receive a 'needs assessment'
- The Care Act 2014 also requires local authorities (LAs) to undertake 'transition assessments' if a child, young carer or adult caring for a child, is likely to have needs when they or the child they care for, turns 18

In adult social care, autistic adults may typically be supported by social workers in learning disability or mental health services, depending on whether they have a dual diagnosis, or by the general social care teams if they do not have a learning disability or mental illness, but appear to need care and support or have safeguarding concerns.

Many local areas have established dedicated disability services that work with children and young people from birth to 25 years, with the specific aim of ensuring that families experience a smooth journey from the early years right through to adolescence and towards adulthood. These services are increasingly multi-disciplinary to ensure that appropriate health, education and social care support is well considered and coordinated.

In children's social care, autistic children and their families may also be supported by social workers from other teams because, for example, their siblings may be children in need for different reasons. They may either be looked after children, on child protection plans, or are involved in private or public care proceedings.

Purpose of the study

The study was conducted to have a better understanding and oversight of 3 key areas in the context of social work practice with autistic people:

- how responsive social workers were to the needs of young adults and their families
- what barriers there were to enable more effective interventions
- how things could be done differently to improve outcomes

The study focussed on current social work practice with autistic children and young people, many of whom had recently had an admission to inpatient mental health settings. There was a keen interest in reviewing the trajectories which had led them there and whether by looking at the history of professional contact with the family, more could have been done to prevent it.

The study offers a series of insights and recommendations to improve the experiences and outcomes of autistic young people and their families. These recommendations will feed into the development of the refreshed cross-government all-age autism strategy. The Autism Act (2009) gave a duty to the Secretary of State for Health and Social Care to publish a strategy for meeting the needs of autistic adults in England. The strategy is being refreshed so that it, for the first time, includes children and young people.

Methodology

The study was undertaken by the Chief Social Worker for Adults (Department of Health and Social Care (DHSC)) and the Chief Social Worker for Children and Families (Department for Education (DfE)), with the support of a team of senior social work practitioners drawn from across England. The study was conducted with advice from Professor Martin Knapp from the London School of Economics and Political Science.

This study used similar methodology used for the Chief Social Worker for Children and Families' study Care Proceedings in England: The Case for Clear Blue Water, published in October 2018.

This methodology enabled a mix of practitioners to come together in this study to:

- review local social work practice through records of care experiences
- meet with social workers that were involved with the families of those whose records were reviewed
- hear directly from the families about their experiences of social work where they were willing to share their story
- meet with senior colleagues and social care practitioners to understand local delivery arrangements

The study was based on fieldwork undertaken across 4 local authorities (LAs) in England between June 2019 and September 2019. The identity of the participating LAs will remain anonymised.

Geographical locations were:

- London
- the North
- the South
- the Midlands

One or both of the Chief Social Workers visited each LA in turn, forming a team in each location which reviewed care experiences and reflected on local arrangements. The teams in each LA site consisted of senior social work practitioners from the other LAs in the study, to ensure a good balance of knowledge and skills as well as to offer different, comparative perspectives.

Annex 1 provides further details on each LA.

Profile of the study group

The study focussed on 61 autistic children and young people, split across the 4 local authorities. Reviews took into account:

- the support they needed
- the support they received
- the impact that the support had on their lives and the lives of those around them

LAs were invited to put forward the experiences of autistic people who met the following criteria:

- category A: autistic people aged 25 and under, including children, who recently moved into an institutional setting – 19 young people were reviewed
- category B: autistic people under 18 years of age, who were currently living in residential placements or schools, and where planning focussed on enabling them to stay in the community and move towards independence – 21 young people were reviewed
- category C: autistic people aged 18 years or over, who had been successfully living independently in the community for at least 18 months, where social work practice contributed to that independence – 21 young adults were reviewed

Age

No particular age limitations were imposed, but the range of autistic people reflected a cross section of ages to ensure good analysis:

- 36 were between 18 and 25 years old
- 19 were under 18
- 6 were over 25

Gender

No particular gender split was imposed, the gender of the autistic people were not determined by the local nor national split:

- 37 were male
- 24 were female

Background

The ethnicity breakdown was consistent with the ethnic makeup of the participating authorities:

- 44 of the study group were from a white background
- 17 were from a black, Asian or of mixed heritage background

Placements at the time of study

- 32 were living in a residential placement or school
- 21 were either in a shared or single occupancy supported living arrangement
- 3 were living with their family
- 5 were detained under the Mental Health Act 1983 in an inpatient mental health setting, with work being done by the social work team to support them on discharge

Care history

- 13 families reportedly felt unable to provide full care for their autistic family member but remained actively involved in their life
- 12 autistic people either were currently or had a history of being 'looked after' or a 'child in need'
- 8 of the care experiences included either, or a combination of, having separated parents, a history of substance misuse in the home, safeguarding or neglect concerns

Findings

The findings below highlight the themes that emerged from our analysis of care experiences in the study, discussions about these experiences with the practitioners involved (and in some instances the family), and broad discussions about delivery arrangements and challenges with the practitioners in each LA.

Overview

We saw examples of effective practice with autistic children, adults and families typically characterised by social workers being the family's key worker at an early stage and providing consistent support.

Most families we talked to said that ongoing support and having one point of contact (for when they needed to talk to someone about their worries) really helped, as did a proactive social work response.

We found instances where only providing interventions reactively led to social care needs being neglected until the situation had escalated to a crisis. Providing a clear, consistent support offer for parents in an early development pathway, rather than support at points of difficulty, were greatly appreciated by those families.

The experiences and conversations we had showed a tendency to use the social work assessment as an opportunity to determine parenting capacity through a child protection lens rather than through a family support lens. Some families are being unnecessarily pulled into the child protection process. Fear of being labelled a bad parent or concerns about being blamed for failing as a parent may limit a family's willingness to seek help.

Some families tried to provide the best possible care but despite their relentless efforts, the teenage years often brought an escalation of distressed behaviour that eventually overwhelmed some families.

There were many good examples of how having a dedicated social worker made a tangible difference to the quality of life of a young adult. Social workers who were equipped to practically help prepare families with new strategies to support their fast-growing children were able to achieve better outcomes from the social work intervention.

Some of the young adults had experienced significant trauma through loss and change, or in some instances from abuse and neglect. This was not always carried well throughout their journey across children and adult services. The details of people's experiences must be reflected throughout their life story so that professionals engaging with young adults, in the transitional years and throughout adulthood, can gain an understanding of their personal history and experiences and how that may impact on them now or in the future.

Families who received consistent social work support early in the life of the child, were more likely to avoid inpatient admissions in young adulthood. Relational continuity is especially important for autistic young adults and their families.

The practice study showed that social workers need to develop key knowledge and skills to work with autistic people and their families, or at the very least be able to readily draw on the expertise of others which can then be applied to their social work practice. This is essential to ensure effective support.

Importance of early and continuous support

Within the cohort of the study, autistic young children were more likely to receive a diagnosis of autism when they had other significant health or care needs. Families of children who had received an early diagnosis of autism were more likely to receive support throughout childhood. They were subsequently less likely to need admission to inpatient care when they became young adults.

Where social workers had full access to information about the family's history, specific needs and strengths, this allowed them to consider what matters most to the family and to provide better tailored and more immediate responses. Effective support strategies included helping to build a network of professional and community support for the family, for example through speech and language therapy, occupational therapy, psychology, stronger connections with kinship networks, school and friends. It was crucial for a safe, happy family life to ensure that the needs of parents, siblings and carers were addressed.

In the experiences reviewed, there was not enough social work support where families were coping with very challenging behaviour. Had this been provided, it might have avoided the family breakdown that often later ensued.

Families received varying levels of professional support throughout the childhood period. Where autism was either not recognised until early adulthood and/or well understood, we found that this led to increased levels of family stress as the autistic young person approached adulthood. In many cases, this resulted in a crisis-driven placement or in the worst instances, hospital admission where the family felt no longer able to support the autistic person at home. This disruption to family life was deeply traumatising for everyone concerned.

Young adults who had been detained in hospital were often diagnosed as autistic much later in life, some not until their first (or subsequent) psychiatric hospital admission. Consequently, many of these families had never received any specialist support throughout the young adult's childhood. Other families had received a very early diagnosis of autism but had not needed support services, were not aware that support was available or in some cases didn't get the support that was needed. The better results achieved following input of early and ongoing support suggested that other less restrictive options might have been more possible when difficulties arose.

Several young people who had similar issues to those who were admitted to hospital, were well supported to move to residential placements from home (or their residential school), rather than into hospital. Conversely, a lack of early support and ongoing proactive social work involvement and support to parents, seemed a missed opportunity to support families through their child's journey towards adulthood. The study found that where the family had a strong, ongoing relationship with a social worker, who understood the nuance of the family story and clearly had the young person's best interests always at the centre of their practice, the young adult was supported to remain at home for longer or supported to organise a planned move to a residential setting.

Ultimately, we found that in the cases where high-quality early support was offered, this helped and improved the quality of life for the individual and their family. However, it is important to note that even with high-quality early and continuous social work support, some young adults' needs were such that institutional care would be hard to avoid, at least at certain points of crisis. It is also important to note that where early support is not offered, this does not mean that good outcomes cannot be achieved, or the right support cannot be accessed, later in an individual's life.

Experience of school and of education, health and care plans

Social work involvement in the development of education, health and care plans (EHCPs) was varied across the care experiences reviewed. Some of the best plans we reviewed were when the social worker had co-ordinated the EHCP, as a key professional working across agencies. We found that social workers tended to be more actively involved when a child was in need, looked after, or on a Child Protection Plan. However, often due to work demands and competing priorities, social workers did not always attend the EHCP reviews, therefore social care needs weren't effectively reflected in the plans. Strong, skilled social work involvement ensures a strong social care focus in the development of EHCPs.

The study found that there was sometimes an overreliance on schools to support children and families, which eventually led to untimely social work intervention at the crisis point. Where social workers had provided additional support through respite or support in the home setting to assist parents and help make adjustments in the home environment, parents reported that this had really helped, so they often felt frustrated that this type of approach wasn't always possible at school.

We found examples of social workers building effective relationships with schools and between schools and families, which particularly helped where the relationship between school and family had been fraught. Social workers should support opportunities to work together with all parties and ensure all the ways to support the child in school are fully explored. It is also important that social workers continue to offer their support during further or higher education, ensuring that they are working across agencies to advocate for the autistic person's wants and needs.

The parents we spoke to felt that there was often limited understanding among practitioners of how personalising the education environment for the autistic person could really help or had limited opportunity to implement these strategies. This experience was more likely in the case of mainstream settings.

Some children were excluded from school when challenging behaviour increased and the school no longer felt able to meet the child's needs. This was particularly and not unsurprisingly when the autistic child was considered a risk to other children. The increase in challenging behaviour often overlapped with the onset of adolescence. For some autistic young people with high needs, we found that better outcomes were achieved when they attended specialist schools that were better equipped to support their needs.

However, even within the specialist school environment, it is essential that staff are available with the requisite knowledge and skills to understand how autism can impact on a young person's wellbeing. Staff should have a confident and creative approach to supporting the young person and their family on a day-to-day basis.

The relationship between school life and family stability is well known and it is no less so for autistic children. Social workers often have a unique insight into how a family functions best and what strategies might be best used to support a child in school. Working in partnership with families and schools to help ensure this information is shared and understood could improve stability and general wellbeing for the child. Where social workers worked closely with schools to coproduce care and transition plans, this led to a more successful transition for the child.

Experience of children's social care

We found that there was a wide range of reasons why families of autistic children were involved with children's social care services. While having social care needs was common, some families were also connected through adoption or fostering, child protection or because there were siblings who were also children in need. Even where the sole reason for contact with children's social care was because of the social care needs of an autistic child, there was a tendency to use the social work assessment as an opportunity to judge parenting capacity through a child protection lens rather than through a lens of social care need. This has long been a complaint of families caring for disabled children. The most common context for support in children's social care is child protection, so even when that is not the necessary focus, it can influence broader practice approaches. Fear of being labelled a bad parent or worries about being blamed as failing as a parent, may limit families' willingness to seek help.

Where the focus in children's social care seemed to be on specific tasks and episodes rather than on longer-term life outcomes and developing independent living skills, preparation for adulthood seemed to be more challenging. As we have said elsewhere in this report, young adults and their families stated that they found it helpful to build a close relationship with their social worker. Where preparation started from an early age and social workers had supported the young adult and family on this journey, fully involving them, it resulted in more successful outcomes in terms of appropriate residential options and/or independent living support in the community or with their families.

We were also particularly troubled by reports we received from families who had been brought into the child protection process because of disagreements with practitioners about how their child's behaviour could best be managed within the home setting. We recognise that we are not party to all the information and are cautious to form a judgement in the absence of all the facts. However, this is a repeated concern that we hear from parents and carers outside of this study in the course of our ongoing communications with families over the years both in our roles as Chief Social Workers and during our many years in practice leadership roles.

While we have no doubt that there will be instances of child abuse or genuine poor parenting, we also think it likely that in some instances, a different approach could be taken to explore the most effective strategies for positive behaviour management that families can use without assuming a child protection strategy is required.

Adolescence as a time of transition and change

Adolescence is well recognised as a major pressure point for families. For all the young adults whose cases we reviewed, adolescence was a period of upheaval and change. Many families tried to provide the very best of care yet despite their relentless efforts, the teenage years often brought an escalation of distressed behaviours that was overwhelming for some families. Change and unpredictability can often trigger anxiety and stress in autistic people, and so significant changes to the body and the impact of hormonal changes on mood were understandably challenging in the cohort of this study.

Parents often reported that they had been able to support their child in the early years of childhood but found it increasingly difficult as the young person, who not only grew bigger and stronger, but sought independence at a level that could not always be safely enabled. This could sometimes lead to aggressive and even violent behaviour from the young person which in turn, led to some families living under enormous pressures. It also often led to school exclusions or contact with the police, having been called to the family home or because of a public incident. On occasion, this also led to family breakdown and placement in residential care or hospital.

Social workers who were equipped to proactively help prepare families with strategies to support their children and to have some contingencies in place, were able to achieve better outcomes from the social work intervention. Anticipation and preparation for challenges associated with the onset of adolescence were evidenced in some instances.

Unsurprisingly, where a child had received an early diagnosis and steady support which changed according to the changing needs of the child, families were much better equipped to manage, both practically and emotionally, the challenges of adolescence and young adulthood. Statutory services that have existing relationships with families should be able to effectively plan for this transition period and be prepared to helpfully manage increased family stress. Effective practice included:

- developing circles of support for families
- anticipating crisis points with necessary plans in place
- providing access to integrated adolescence services including youth services, leisure services, employment support and youth offending teams
- providing access to respite care and positive behavioural support for the family

We also saw great examples of social workers in 0 to 25 years' teams, leading on transitions with backgrounds in working with both children and adults. These teams had been set up to provide continuity and consistency of care from birth to the age of 25, as appropriate. They worked with and supported parents with the additional challenges of the onset of adolescence as their child grew physically and emotionally, at the same time as moving to secondary school or from school to college.

Supporting parents with the demands placed on them during this period helped reduce their feelings of being overwhelmed. By fully involving the whole family, using person-centred planning approaches and ensuring that there was a focus on what the young person wanted and needed, social workers were able to discuss preferred options for the future, using a strength-based approach.

Where there was no transition team in place, in some instances social workers from children's and adults' services worked closely together to co-produce transition plans. This led to good outcomes for the young person and their family. For example, we saw examples of dynamic assessments during this critical period which harnessed the resources of the wider family and social network, and a wide range of other services.

Positive outcomes were also achieved where social workers worked with inclusive adolescent services and were able to support autistic young people to access community-based activities, for example, employment skills preparation.

Social workers are able to enable the young person and their family to manage the frustrations and challenges of adolescence as well as share their pride and sense of achievement, as a young person develops. We found there were better outcomes where social workers helped families consider, through mediation, how autistic young adults could separate from their family and start to live more independently, while remaining at home or moving out into in the community.

Overall, social workers were better able to support families through adolescence where they:

- had established and maintained a good relationship with the young adult and their family
- had been transparent and consistent in their approach
- had provided practical and holistic support at times most needed

Trust and confidence in the social worker was essential for all families we consulted.

Diagnosis and co-occurring conditions

Diagnosis and co-occurring conditions

Many of the young people had multiple needs in relation to their autism and were often assigned to learning disability or mental health services. While social workers in learning disability services were well equipped to respond to their needs, sometimes a young person's autism was overshadowed by their learning disability diagnosis. This was even more prevalent where the young adult also had mental health conditions, with mental health services not always fully understanding, or catering to, their needs relating to their autism. This sometimes led to a misunderstanding about the root cause of behaviours of concern and even misdiagnosis. For example, we found an overreliance on mental health services for autistic young girls who were sometimes misdiagnosed with emotionally unstable personality disorders. In some instances, Child and Adolescent Mental Health Services did not accept referrals as they felt they did not have the knowledge and skills to work with autistic people.

Where services had extended their remit and ensured that practitioners were sufficiently skilled to address needs related to autism as well as learning disability and/or mental health, this was proven helpful to families. Where there was a social worker with a specialism in autism, they were able to provide more tailored advice and practice supervision to colleagues. This seemed to improve the social work response and lead to better outcomes by focussing on appropriate communication methods, building on strengths and co-producing care and support plans with the individual and their family.

Upon reflection and conversations with practitioners, we felt that stand-alone autism services integrated with health and care services could include specialist clinical staff and social workers. This could lead to more creative and personalised service development as well as earlier access to sensory reviews and support to improve living environments. The downside of this may be that services become too siloed in their approach and would not be sufficiently positioned to address other needs related to learning disability or mental health, or indeed wider social needs. The option of extending service remits to neurodevelopmental disorders generally, as is happening in some health services, could apply to social care as well.

In some instances, young people waited too long to access services or did not meet the criteria. For example, an integrated learning disability service was not commissioned to provide services to autistic people without a learning disability diagnosis. This meant that the generalist children or adult social care teams were responsible and did not have the capacity or expertise to respond effectively. There is also often variation in commissioning priorities where there is more than one clinical commissioning group (CCG) in a council footprint. This resulted in different offers to people depending on which LA they lived in, with some including autism in the service specification and others not.

Many of the autistic people in this study had sensory needs as part of, or alongside, their autism needs such as visual impairment or intolerance to certain noises or environments. There is a need for social workers to work closely with health services to better assess these needs and ensure they are met effectively. Autistic people are more likely to have co-occurring physical and/or mental health conditions which can go undetected due to communication difficulties or overlapping symptoms. Where there was a jointly produced care plan between health services and social workers, this led to positive outcomes for young adults and their families.

The experience of living away from home

Most autistic young people in the study who were living in the community were in supported living schemes with others or living on their own with support input ranging from 12 hours per week to 24-hour support. They had either moved from hospital, from residential placements or from living with their families. Transition teams would have been involved to support the young adult and their family, complemented by proactive leadership and co-ordination from the social worker.

In the experiences we reviewed, where young adults and their families were involved in recruiting their support staff, this enhanced the success of the supported living arrangement. The complexity of their needs and the intensity of support required were often very significant and there were good examples of wellbeing and inclusion outcomes for the young adults.

In some cases, admission to a residential placement led to a young adult being assigned to a less experienced practitioner who only visited them once or twice a year to review their care needs. This was often due to lack of resources meaning delegation of tasks to other care staff from social workers. This did not support consideration of more community-based independent living arrangements for the future, as it was focussed on ensuring providers were meeting the contract requirements.

Some young adults were accommodated in schemes with other people who they were not well suited to which resulted in a further change of accommodation. This was disappointing and disruptive for both the young adult and their family.

Some of the practitioners who we interviewed had very limited contact with the young adult when they were placed in institutional settings which led to a lack of oversight and meant that the young adult's social needs and discharge were often not well supported. Better outcomes could have been achieved by social workers maintaining contact with young adults in inpatient settings and continuing to act as an advocate across services.

Information exchange, case recording and collecting data

Children's services often had comprehensive records of the young person's life, but this was not always transferred to adult services when the young person becomes 18. This was particularly an issue given the multi-agency nature of support in most cases which sometimes meant that professionals were often unaware of key aspects of the young adult's early life, such as the impact of trauma or other diagnoses. This left families having to repeatedly tell their story to different agencies and professionals within agencies.

In the experiences of this study, adult services did not always make good use of case summaries on electronic systems to make sure that a person's story, strengths and key life events were reflected in their care records. Consistent capture of the details about a person's story can help ensure smooth continuity of care and allow social workers to understand the person and plan effectively.

However, we found some good examples of practice in adult services in the use of pen pictures or one-page profiles which captured the person's needs. These captured the person's strengths, likes and dislikes, and offered a focus on possibilities for developing more independent living skills, social connections and inclusion in community life. Some care reviews were written in the first person by the young adult themselves with support from their social worker.

When having a social worker made a difference

The study showed that where social workers sustained the relationship with the young adult while they were an inpatient, and with professionals in mental health hospitals, better outcomes were achieved including ensuring that the right care and support arrangements were in place for discharge.

There were good examples where social workers had enabled young adults and their families to challenge decisions to continue to keep them in inpatient care, which made a positive difference and led to timely discharge planning.

For those young people who were admitted to hospital following an assessment under the Mental Health Act, the importance of the skills and understanding of the social worker was vital. One example involved a psychiatrist being concerned that the autistic young adult would not make eye contact. The social worker was able to explain that not making sustained eye contact was part of their autism, rather than them not fully engaging.

Where social workers were able to ensure that the voice of the young adult was considered and balanced with the parent's views, this often led to positive experiences in residential placements or supported living arrangements.

The consensus from the care experiences we analysed, and the families and professionals we spoke to, was that social work's role is critical and can help significantly with transition issues. This reinforces the need for social workers to form close relationships with autistic people and their families where they can really understand people in the context of their lives, communicate using methods and at a pace that works for the young adult, and to explore a range of options together to enable them to get on better with their lives.

In addition, similar themes were found from the lessons from the DHSC-sponsored Named Social Worker pilot for people with learning disabilities and autistic people, demonstrated that having assigned social workers who can take the time to really get to know the person and their family, build trust and a sense of hope, and who are confident in using their professional judgement to take the best course of action, made a positive difference. Additionally, expertise in working specifically with autistic people, employing a broad set of communication methods, creative tools and a robust understanding of the legislation, enabled social workers to advocate for people and ensure a more holistic response to their needs across health and social care.

Recommendations

The following recommendations have been formed following the findings from the care experiences we reviewed, the conversations we had with families, the conversations we had with practitioners to reflect on the experiences we reviewed and on broader challenges in local practice and delivery, and the general practice expertise of the Chief Social Workers.

1. We recommend that the refreshed autism strategy:

- acknowledges the value that social workers' professional knowledge and skill base can bring
- ensures inclusivity and removes barriers to participation
- embeds personalised approaches in practice
- enables choice and autonomy using the least intervention possible to ensure safeguarding
- promotes the social work profession as the lead for upholding this value base in practice, when working with autistic people

2. It is crucial that social workers maintain contact with autistic people regardless of their current setting, and that they build strong relationships across agencies. This is especially important when an individual is placed out of the local authority area. To ensure delivery of agreed outcomes and that care and support plans are coproduced, autistic young people who are admitted to an NHS Assessment and Treatment Unit or residential setting should have a named social worker who has statutory responsibility for maintaining contact with them and their family.

3. To ensure a proper national infrastructure in England, a national network of specialist social workers and other practitioners (for example, mental health nurses, teachers, youth workers etc) should be established to ensure best practice and new evidence in working with autistic people is shared and adopted in practice.

4. Given the success of the DHSC-sponsored Named Social Worker pilot and the findings of this study, we would like LAs to consider having a qualified social worker with specialist knowledge and skills to work with autistic people, and across the full spectrum of health and care. This is supported by the NICE quality statements which set out that autistic people should be offered a named key worker to coordinate care and support.

5. A supply of practitioner expertise who can deliver staff development opportunities in their local areas, alongside hearing from families and autistic young people, should be created. With this in place, statutory guidance should require a more specialist approach to practice whether that is through an integrated specialist service or specialist workers within wider integrated services. Where commissioners and social workers worked together in a joint approach, this led to better care options being available for people.

6. The What Works Centre for Children's Social Care should be funded to build the evidence base of the most effective strategies for supporting families in the early years and to continue to look after their children throughout adolescence and beyond, either at home or in the community.

7. The recently announced requirement for mandatory training, in line with the Tier 3 competency framework for all social workers working with autistic people, will contribute to improving practice. In addition, qualifying programmes for social workers must cover knowledge and skills required to work with autistic people.

8. We warmly welcome the announcement that the NHS services to children and young people with specific conditions including mental health needs will extend their service eligibility to age 25.

9. Services who are working with children and young people, and do not yet do so, should implement the Department for Education's 7/7/7 Practice Framework which promotes whole system, strengths-based, systemic social work practice, within multi-disciplinary contexts. Where we saw holistic, strengths-based practice being implemented in this study, it allowed for social workers to build a trusting relationship with young people and their family and a more in-depth understanding of the impact of adolescence on autistic young people.

10. The study showed the importance of practitioners having the right knowledge of autism and how crucial it was to embody best practice. We encourage the National Institute for Health Research to review their research programmes to ensure that progress is made in determining best practice for supporting autistic young adults to live independently or in community-based settings. Autistica's rapid evidence review of social care for autistic adults, published in June, showed the lack of high-quality research in this area.

11. Principal social workers should embed the Capabilities Statement for Social Work with Autistic Adults and the Social Care Institute for Excellence (SCIE) guidance on preparing for adulthood in their practice of their teams and ensure LAs and NHS learning and development plans support social workers to meet the required capabilities. The existing Capabilities Statement should be further developed to include working with autistic children and their families.

12. Sustainability and transformation partnerships (STPs) and integrated care systems (ICSs) must ensure that there are local agreements, protocols and mechanisms between health, social care and education organisations to ensure that information about a young person's needs, wishes, strengths and aspirations follows the person through transitions between services.

13. STPs and ICSs must ensure that there is a dynamic risk support register in the local area, jointly owned by health social care and education, which identifies children and young people at risk of admission to an institutional setting, is kept up to date, is used by organisations to plan proactive, flexible and joined up support for children and their families most at risk of admission.

Annex 1: the local authorities in the study

Council A

Council A is a large upper-tier authority.

- It has a population of over 1.18 million, making it one of the most densely populated shire counties in England
- 81% of the population are white British
- The 'Index of Multiple Deprivation' shows that the county is consistently one of the least deprived areas of England. However, the general prosperity of the county is not evenly spread, and there are a number of pockets of deprivation and considerable variation across the county

Council B

Council B is a unitary authority.

- It has a population of over 370,000
- 96% of the population are white British
- It has a mixed economy of agriculture and industry, market towns and urban centres
- Overall, Council B is a fairly affluent LA but has significant areas of deprivation, both urban and rural

Council C

Council C is a unitary authority.

- It has a population of over 300,000
- 97% of whom are white British
- It includes former coalfield areas – prosperous settlements where many residents commute to a neighbouring conurbation and extensive sparsely populated rural areas
- There are marked differences in healthy life expectancy between its most and least affluent areas

Council D

Council D is a unitary authority in London.

- It has a population of over 250,000 with the seventh-highest population churn in England
- Over 100 languages are spoken in its schools
- 60% of primary school pupils have home languages that are not English
- It has thriving business, health, cultural and university sectors
- Overall, Council D is a thriving dynamic local authority with high levels of employment but has significant areas of deprivation sitting alongside areas of pronounced affluence

Annex 2: anonymised examples of care experiences reviewed

Chris's story

Having adopted Chris at 6 months old, his adoptive parents struggled with his behaviour from the very early years. Chris was eventually diagnosed as autistic with attention deficit hyperactivity disorder, oppositional defiant disorder, anxiety and mood lability symptoms, foetal alcohol effects and learning disabilities. They felt they could have had more post adoption support from social care in relation to managing the challenges caring for a baby and toddler. They reported that his social worker was relentlessly focussed on his best interests and the family's best interests, knew and understood him well, and was the key professional who held his story and worked hard to join up the gaps between health, education and social care, stepping up to co-ordinate the work of the multi-disciplinary team.

After diagnosis, the family did not experience expert advice and support from professionals such as psychologists, in how best to manage Chris and felt that the school offer was not bespoke to his needs. He became increasingly disturbed once he moved to secondary school. He refused to go to school and was placed in a specialist children's home when he was 12 following a serious assault on his father. The family were no longer able to meet his needs at home. It was a painful process for his parents. They continued to remain fully involved in his care and support planning and felt that the social worker should have more control over decision making as it often seemed decisions were made at a distance from them and their young person.

While in the care home, Chris was supported with staff caring for him on a 2:1 basis, as his behaviour could be violent and unpredictable. Although the placement was successful with Chris settling and being a lot calmer and engaged, as he entered adolescence, he outgrew the placement and he wanted opportunities for greater independence. The plan was for him to move to a provision that could better support his transition into adulthood. Delays with identifying a suitable option resulted in exacerbation of his distress and violent behaviours after which he was detained under the Mental Health Act. The family supported a brief admission to keep him safe and calm. He was been detained for 5 months and the plan was to discharge him to appropriate community-based provision, once identified. Delays in finding a suitable option once again had a negative impact on his well-being. The need for appropriate community provision with skilled support remains a significant gap in services.

Mary's story

Mary is 25 years old and is autistic.

Although different agencies appear to have had concerns about Mary as a child (children's social care had been involved with Mary when she was 13 – she was on a child protection plan which lasted for a year before social services input ended after improvements in parental care), there was little evidence of a multi-agency approach in planning appropriate co-ordinated support. The social care team did not seem well placed to understand and work with the unique issues relating to Mary's autism, and to ensure her family were provided with access to appropriate advice and support.

By 18, Mary was an elective mute, was under 5 stone and was severely physically and emotionally neglected. She had been living at home with her parents until safeguarding concerns were raised with adult social care services. She was known to be wearing nappies, being pushed round in a pram by her mother and treated as though she was a baby. These events appeared to coincide with her father's death and the fact that her mother was unable to look after Mary on her own.

Mary was provided with an adult residential college placement, but this was unsuccessful as the college was unable to cope with her behaviours. Mary was then placed in a specialist placement for people with learning disabilities and autistic people and was allocated a social worker in the mental health team, as she did not have a learning disability. The social worker has worked with Mary over the last 4 years, has gained her trust and has worked closely with the nursing and care staff to co-ordinate support to help with her gain independent living skills.

Mary is now attending to her own personal care needs, eating healthily and attends art college. She can read and write, is considered bright and is an excellent artist.

Joe's story

Joe is 25 and has lived in an NHS secure unit for 6 years.

Joe has a very long history of involvement with statutory services. He was diagnosed with autism, aged 4. He had lived with his mother up until this point, but she struggled to cope with his needs as she had her own mental health issues, and she found Joe's aggression and withdrawal from her very difficult. Joe had 3 different foster placements, each of which broke down. At 16, he was admitted to a hospital unit where he remained for 3 years. He was then placed in a residential unit up until his current secure placement.

He is now diagnosed with attention deficit disorder and a possible antisocial personality disorder, as well as his original autism diagnosis. His extreme (he had refused to wash for over 12 months) and violent challenging behaviours have resulted in his detention in secure settings. Through the support of his social worker, focussing on what mattered most to him, he was able to say he wanted to live in a bungalow. Plans were put in place to find a suitable option and the social worker co-ordinated and led the work of the multi-disciplinary team – this included positive behavioural support workers, nurses, a psychiatrist and the staff from the care provider.

His mother was also involved in the planning. He moved into his bungalow in a secure supported living scheme, after 18 months preparation. He now attends to his own personal care and has started community outings and is socialising with others.

Joe's story highlighted how essential it is for social workers to have a good understanding of autism and how that can impact on the young adult, together with a shared decision-making approach. Understanding the unique way in which Joe saw the world around him and communicating with him using words and pictures that he understood changed the conversation and created the right conditions for him to succeed. This is intensive and painstaking work which requires the capacity and skills to get to know and understand the person and access to different interventions and techniques to support the person and their carers, such as positive behaviour support and communication methods.

The professional confidence of the social worker together with S117 Mental Health Act requirements providing statutory responsibility for leading on a person-centred approach, gave the social worker the leverage to pull the professional disciplines and agencies together. This delivered an effective care and support plan for Joe, taking a positive risk enablement approach to protecting his human rights and the chance to have the same opportunities as other young people. When the multi-disciplinary team used a person-centred approach, this had a positive impact which was meaningful to Joe and achieved better quality of life for him and his family.

Sola's story

Sola is 25 years old.

Sola came from Nigeria at the age of 6 to live with her aunt and cousin. Her parents live in Nigeria as do several of her siblings. She and the family were well supported by health, social care and education. Social care has been involved from the time she arrived, putting in place support for needs arising from her learning disability, sensory needs and autism. Support included regular contact with a social worker, an occupational therapist making environmental adjustments to the home to reduce sensory triggers, positive behaviour support in the home to assist the family to respond effectively to the emotions she was communicating and regular contact with the social worker. Support was also provided to ensure that Sola could occasionally visit her family in Nigeria.

The social worker established a trusting relationship with Sola and her family carers and they had confidence in her, stating that she took time to understand Sola and the family and used appropriate communication. They felt she always worked collaboratively with them and helped them maintain their support and involvement.

Sola lived in the extended family home and went to a special school and had regular residential respite weekends in a locally based provision which she considered her weekend house. On finishing school, she worked in a supported employment café for 2 days a week, which gave her the opportunity to be out in the community with others. Sola wanted to move to live more independently from her family, which her extended family supported. A supported living scheme was identified and although it took some time, preparations were made for Sola's move. A multi-disciplinary approach was taken to assessing the suitability of the scheme, the environment and the compatibility of the other people who would be living in the scheme.

The support staff had specific training on supporting autistic people and opportunities to get to know Sola in her home setting. The family were involved as part of the support circle for Sola along with the care support workers. Staff are available 24 hours to provide the support required.

Sola has been living in the scheme for 2 years and has become more independent, more confident while still needing ongoing support with her emotional needs and ongoing advice regarding managing relationships. Sola had a social worker who was responsible for all of those living in the scheme which had been developed from earlier iterations of the previously mentioned Named Social Worker pilot.

The social worker felt the multi-disciplinary approach to ensuring the suitability of the scheme, the explicit sign up to a positive risk enabling approach and regular opportunities for the team to have reflective supervision time to review and think things through, had helped in achieving the positive outcome for Sola. She and the family also felt that this model of care and support reduced the risk of loneliness and isolation for Sola.

Annex 3: anonymised statements from parents

Parent A

"It was only when we hit a crisis that we received support.

"This was several years after diagnosis and despite asking for some general support prior to this, we were now dealing with a very distressed child who was exhibiting violent behaviour as a result of the increased anxiety levels. We readily asked for help from several professionals, including paediatrician, school, disability social worker and even CAMHS… There was no support to deal with the violent behaviour.

"I have been told that I would need to use cushions, or phone the police. Also, that we as parents must not physically intervene when our child is like this because we haven't been offered the training that schools and other professionals receive. I can understand this however I think it is important to educate parents in safe management techniques to use in these situations. I have found that there is only so much help that services can actually offer, perhaps through lack of understanding or funding issues, etc. What is not helpful is that some of the services add to the stress that parents are generally under – they seem quick to try and blame the parenting approach and home environment for the issues that occur. If there is no easy solution to helping parents manage the challenging behaviours, the services need to acknowledge that there is a gap in the system and continue to try and offer help when they feel they can. However, the reality is that they address the issue in a more unpleasant manner and make parents feel they are to blame for the difficulties and add pressure for the parents to fix the issues, without being given the necessary tools.

"This approach adds unnecessary distress to what is already a stressful situation. Services need to be respectful of the complex needs of families who have children with additional needs and to gently offer the support, training, and encouragement needed at this time, to acknowledge there isn't always a quick and easy answer, and to appreciate that this is actually alright and that with encouragement and support families can cope."

Parent B

"I am writing to you as the parent of a child with autism, and also as someone who works in social services. I have completed my LA autism training for staff and was the first parent to attend who had a child with autism.

"I was able to share real life experiences.

"It should be made compulsory that courses have real life experiences built in, as well as have input from autistic people, as too many generalisations are made, such as give your child a bath to calm them down/relax them. For my son that would be the complete opposite.

"I then went on an autism champions course which was led by a facilitator with autism. It was a great course and really opened up the eyes of staff with many saying they now would have acted completely differently.

"Life-changing decisions for these children based previously on ignorance!

"Autism training should be a part of the core social work training and should be a mandate for all social workers already qualified."

Parent C

"It has taken us, and many other parents, a very long time to firstly get a diagnosis for our children.

"From approximately 13 months I knew my child wasn't quite the same as other children his age. I flagged this up with various professionals and it took until he was aged 9 before we got a formal diagnosis – a number of professionals have agreed that the behaviour was certainly meeting criteria for autistic spectrum disorder. We felt that we had missed out on 9 years of intervention, training, and education, so that we could understand autism and its various characteristics.

"After diagnosis, we received no training, no help, no support. We would have welcomed all the advice and support on how to tailor parenting to best suit an autistic child.

"We learnt mostly through asking parents who had similar difficulties and from looking at the internet."

Parent D

"My son wanted to die at age 7 rather than go to school as he was getting up to 20 to 30 time-outs a day, until I insisted that they get autism experts in to observe him. They did so and recommendations were put in place which instead of him being treated like a naughty child on a chair outside the classroom, he had a dark tent and a workstation for when he was overwhelmed.

"It has been a long road, but he is a bright boy and is doing so much better because the staff went on courses and now understand how best to support him at school."

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