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GUIDANCE

Guidance for health professionals supporting groups with specific complex needs who are or have been shielding

SCOPE

This document is aimed at psychologists and other health professionals supporting adults who are or have been subject to shielding, who have additional complex needs or considerations, including adults with learning/intellectual disabilities, autism spectrum conditions, and/or those living with dementia. The considerations may also be relevant for those living with long term health conditions and their families. People living with these conditions often live with hidden disabilities and the difficulties they face can consequently be less obvious to services and society due to Covid-19.

We specifically focus on those in the 'high' risk category defined by the UK government but we recognise that many people not officially in the 'high risk' category may have been shielding and therefore may face similar challenges, especially those shielding others, or those in 'moderate risk' categories.

There are other resources for professionals and the public on people who are shielding and working with people with intellectual disabilities, autism or dementia on the [BPS website](#).

A NOTE ON TERMINOLOGY

Throughout this document we have used the term 'vulnerable' as this is the language used by the government for guidelines and policy. We acknowledge the criticisms regarding this language; describing individuals as 'vulnerable' can be understood as locating the challenges within the individuals, rather than acknowledging the difficult situation that people are in. This also links with disability rights regarding not individualising such issues within the person.

INTRODUCTION

The UK government announced on 23 March 2020 that people in the ‘clinically extremely vulnerable’ category should take extra precautions known as ‘shielding’ for an initial period of 12 weeks. This was extended until 1 August 2020 and continues to be under review. The restrictions and guidance varies across the four nations. Shielding individuals will be those who are at high risk of serious or fatal consequences if they are exposed to Covid-19. The research regarding individuals that fall into the category is continually changing. The NHS describes levels of risk as high or moderate on the [NHS UK website](#).

People with intellectual disabilities, autism or dementia will be regarded as ‘vulnerable’ adults given these conditions, and many will also have been regarded as ‘clinically extremely vulnerable’ due to additional underlying health conditions. These groups have also been disproportionately impacted by Covid-19, as they may experience health inequalities and have an increased likelihood of additional health conditions that can increase their risk of dying from Covid-19, and evidence has shown increased mortality rates over this period.

Despite the likely increased need for shielding, people with intellectual disabilities, autism or dementia are likely to experience an increased dependency on other people for care and support in their day-to-day lives. For some, the nature of the reliance on care from others, or living in residential care homes or shared supported living environments, even whilst shielding, has further increased the risk of contracting Covid-19. The care people receive has also been impacted over the lockdown and shielding period; for some lockdown may have resulted in a reduction in support available, whilst many others may have experienced significant changes in how this care has been provided.

IMPACT OF LOCKDOWN AND SHIELDING, AND THE PAUSE TO SHIELDING

Whilst some people with intellectual disabilities, autism or dementia may have, at least initially, experienced lockdown conditions somewhat as a respite from social pressures, for many the extended period of lockdown and shielding has resulted in increased challenges. This included greater social isolation and loneliness, reduced contact with loved ones and carers, lack of access to routine activities, and associated increased distress which may show itself as anger, frustration, anxiety, sadness, grief, and/or behaviours that present challenges. People living with dementia have reported that social isolation has resulted in a lack of stimulation and therefore a feeling that their dementia is progressing more rapidly. This has led to fear about the future and uncertainty whether they will be able to resume the level of independence held before lockdown.

Prior to lockdown people living with dementia were on a cycle peddling slowly towards the end of their dementia; lockdown put us in a fast car speeding on a motorway towards that end. After lockdown, we have got to get people out of those fast cars and back on their bikes, in some cases people will need a tandem to help them along.

(Tommy, Living with dementia)

Equally, for some, the lockdown and shielding period may have afforded some opportunities for changes in people’s support or engagement with activities in new and improved ways, and it should not be assumed that all people want to return to the way things were before lockdown.

Therefore, there may be multiple tensions now for people with intellectual disabilities, autism or dementia, and those who support them, around the governments advised pause to shielding.

As with others who have been shielding to date, there are likely to be understandable, normal and self-protective anxieties about whether the risks of contracting Covid-19 remain high and therefore whether coming out of shielding is currently physically safe, particularly those who have been regarded 'clinically extremely vulnerable'. This is likely to be exacerbated by the ever changing nature of the condition and associated recommendations and guidelines. There may also be anxieties for the safety of people with intellectual disabilities, autism or dementia who struggle or are unable to follow safety precautions outside of shielding/lockdown, for example, maintaining social distance or tolerating the wearing of face masks. However there may also be a wish for life to return to the way it was before lockdown, and to be able to access routine activities and support. The idea of ending shielding may be experienced as a positive by some, but as a pressure by others.

However, despite the end of lockdown and shielding, we know that life is not returning to the way things were before, so things still look very different to life pre-Covid-19. We also acknowledge that restrictions, local lockdowns and other government advice may change rapidly over the coming months. For people with intellectual disabilities, autism or dementia, understanding the current situation may be very challenging e.g. ending shielding but still not being able to access previously enjoyed activities; routine health or other appointments happening in different ways. This may result in increased stress, anxiety and psychological distress.

As the UK has been coming out of lockdown, guidance has been less clear-cut, resulting in confusing messages which is likely to be particularly challenging for those with additional communication needs. People with intellectual disabilities, autism or dementia, coming out of shielding may feel unclear about the expectations around how they, and others, need to behave to ensure they remain safe. This uncertainty and the changing situation has the potential to increase anxiety and psychological distress both for the individuals themselves and for those who support them. The nature of hidden disabilities may mean that individuals' support needs are not always recognised, which can lead to inappropriate, unhelpful or distressing responses from others in the community.

With lockdown I felt lonely. I didn't have a letter about shielding but my brother told me I should because of my heart operation. After lockdown, I felt a bit nervous about using a mask; sometimes I feel sweaty and can't breathe. When I went to the supermarket, there were so many people in the shop, I felt nervous about going in. In the shop they told me if I pick up something I have to buy it, I can't put it back. They talked to me like I was a bit of dirt. I told them I have a learning disability. They said we don't know what you've got, all we're doing is talking to our customers.

(Alex, person with learning disabilities who lives alone)

RECOMMENDATIONS

Professionals working with people with intellectual disabilities, autism or dementia, who are coming out of shielding will need to consider the following, grouped as considerations at the individual, service and community levels:

Individual level

Delivering individualised health advice tailored to the person rather than generic advice.

Ensuring that clear, tailored communication is provided on the key messages around staying safe whilst coming out of shielding, e.g. around social distance, hand-washing, use of masks. People should be given these messages in ways that are accessible to them, e.g. videos, easy read, social stories. Key messages are more likely to be retained, understood and followed if they are repeated and updated as the situation or guidance changes.

Being aware of the increased health risks people with intellectual disabilities, autism or dementia experience, and therefore understanding the increased (natural, understandable and self-protective) anxieties these individuals, and their carers, may face when they are coming out of shielding.

Taking time and a person-centred approach to review how individuals want to live their lives after shielding. Consider where lockdown may have forced changes or created new opportunities for engagement with activities or new interests or routines, or new ways of providing health services, which people may want to continue to incorporate into their life after shielding.

If it is necessary to restrict people's movements as a result of guidance there is a need to ensure compliance with the [Mental Capacity Act](#) and [Liberty Protection Safeguards](#).

Service and systems level

Delivering support for people to come out of shielding at a pace that feels psychologically comfortable and physically safe for them as individuals and for those who support them. This may mean offering a hybrid service which offers both face to face and remote working, or adaptations to the services for some time.

Considering that some people will be less able to access services delivered with technology due to digital poverty, ability or familiarity. Thought should be given to different methods of enabling access and delivering care.

Providing clear communications about what people with intellectual disabilities, autism or dementia can expect from their services including the wearing of PPE and other hygiene or safety considerations.

Taking a proactive approach to considering and understanding the experience for these individuals coming out of shielding, incorporating the values of positive behaviour support where appropriate. This includes understanding the potential impact of changes to previously familiar environments, activities and support and taking steps to mediate this, including appropriately preparing people for these changes (e.g. social stories, visual aids, easy read information, videos), considering in advance what situations may trigger psychological distress and avoid these where possible, or where not possible to avoid, consider how to manage distress in advance (e.g. consider alternative activities, practice relaxation strategies/soothing activities/distraction to manage distress).

Maintaining a stance of compassionate understanding for the challenges individuals and their support system may face in coming out of shielding.

Working closely with carers and others supporting those coming out of shielding to also understand their concerns and worries.

Community level

Raising awareness about hidden disabilities and ways of supporting people living with these conditions during the current situation. For example, this may include promoting the use of [Sunflower Lanyard Scheme](#), or considering use of cards stating exemption from wearing face masks etc.

Working with communities to understand the challenges faced by some groups in adhering to current safety measures. For example, increasing understanding and recognition of hidden disabilities; encouraging accessible signage about safety measures or supporting community groups to facilitate appropriate access.

FURTHER RESOURCES

Further resources including links to accessible information can be found in [Covid-19: Meeting the psychological needs of people with learning/intellectual disabilities, and their families and staff](#) (BPS, 2020).

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