Words That Carry On

IN YOUR WORDS

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About us

**Words That Carry On** is a fund dedicated to investing in mental health research. It has been set up in memory of Lindsay Riddoch, an ardent advocate for better mental health services who was intent on ensuring people who lived with mental health problems had their voices heard.

Lindsay struggled with mental health issues over an extended period and spent the last eighteen months of her life in closed institutions. The ongoing experience made her a powerful and effective advocate of better mental health provision and all that implies.

The Fund is very grateful to all those who contributed their time and thoughts to the research scoping survey which focused on both autism and personality disorders. We wanted to engage with others to make sure that the research we commission is seen as a priority by the sector, is informed by experts by experience, and has potential impact with recommendations that result in action.

The fund is managed by Lindsay’s family and friends with the support and experience of the McPin Foundation which hosts the fund for us. You can read more about us at: [www.wordsthatcarryon.org](http://www.wordsthatcarryon.org)

**Fiona Riddoch**
This piece of work has been carried out to help us decide how to invest our fundraising efforts to support research to benefit people who associate with or are affected by the diagnoses of autism and/or personality disorder. We wanted to hear from others – people with experience of mental health issues and/or autism, practitioners, family and friends, the wider concerned community. We knew this wasn’t going to be a simple task.

The survey was written with the input of people who knew Lindsay and the topics that were important to her. We piloted the survey to check wording of questions and ease of completing. We ended up with three sections:

- Asking people to rate nine suggested topics research, in terms of how important they are to fund and suggest new topics;
- Asking people to tell us of the nine suggested topics which one they would prioritise;
- Asking for some summary details about themselves so we know who responded.

The survey was made available using survey monkey, an online survey platform. It was promoted on Twitter, through the newsletter of the McPin Foundation and Words That Carry On. It was also promoted through word of mouth. The survey was open and collected responses between December 2018 and February 2019.

Note about language

We recognise the contested and controversial nature of the label of personality disorder. Diagnostic categories and the medical model have been used to describe a group of behaviours that people can demonstrate. In the absence of an acceptable alternative, we use the term personality disorder to describe the group of people who are given the diagnosis of personality disorder, never that they are that disorder. However, we encouraged responses drawing on alternative frameworks, models and language, particularly those which give voice to people with lived experience. Abbreviations used in quotes have been left as they were, however we are aware that many people with autism would prefer not to use ‘ASD’, just as those with personality disorder may prefer not to use ‘PD’.
Who helped us?

We were really pleased with the number of surveys received – 358 people took part. This included a range of mental health professionals, service users and their family/friends (see table one). We were interested in people’s expertise, many respondents had experience of more than one perspective: 103 people had sought support for both autism and mental health, and 87 mental health service users (25 for autism) also worked in the field of mental health. Thirty-two of those seeking support for autism (67 for mental health) also worked with autism. Of the 150 mental health workers, 73 reported also working with people with autism.

Table 1: Relationship of respondents to mental health and autism (ticked all that applied)

<table>
<thead>
<tr>
<th>Response category</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have used / do use health services or sought formal support for my mental health through a GP or secondary services.</td>
<td>223</td>
</tr>
<tr>
<td>I have used / do use health services or sought formal support through a GP or secondary services for my autism.</td>
<td>115</td>
</tr>
<tr>
<td>I have been involved because a member of my family or close friend has experience of seeking support for mental health problems</td>
<td>146</td>
</tr>
<tr>
<td>I have been involved because a member of my family or close friend has experience of seeking support for autism</td>
<td>122</td>
</tr>
<tr>
<td>I work with people who have mental health problems or the area of mental health</td>
<td>150</td>
</tr>
<tr>
<td>I work with people with autism or the field of autism</td>
<td>107</td>
</tr>
<tr>
<td>Other experiences and connections</td>
<td>84</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>947</strong></td>
</tr>
</tbody>
</table>

Further analysis of how people identified themselves, based on the categories above showed an overlap in some areas. Thirty-four percent of respondents reported accessing only mental health services, whilst just three percent had sought formal support for autism only and 29% had accessed both. This may suggest that a large number of those receiving a diagnosis of autism had previously been assessed in mental health. The remaining 34% did not access services but were either working in the field, friends/family members of those with either autism or mental health diagnosis or had another connection.

Sixty percent of mental health service users also worked in the field of mental health, whilst no autism service users did (although where people identified as both this figure was 36%). For those working in the field of mental health and/or autism, just over a third (36%) had a work-related connection to both mental health and autism, with one third for mental health and 20% with autism. Half (50%) reported a close friend or family member as being a service user for either mental health, autism or both.
We asked people to rate nine topics using a five-point scale from not important at all to vitally important (a full description can be found in appendix one) for the following:

**Table 2: Priority ratings of topics by percentages (N=356)**

<table>
<thead>
<tr>
<th>Grading / %</th>
<th>Topic 1</th>
<th>Topic 2</th>
<th>Topic 3</th>
<th>Topic 4</th>
<th>Topic 5</th>
<th>Topic 6</th>
<th>Topic 7</th>
<th>Topic 8</th>
<th>Topic 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitally important</td>
<td>49.30</td>
<td>48.60</td>
<td>46.48</td>
<td>59.83</td>
<td>55.90</td>
<td>37.18</td>
<td>51.27</td>
<td>53.24</td>
<td>28.37</td>
</tr>
<tr>
<td>Fairly important</td>
<td>37.75</td>
<td>37.36</td>
<td>34.37</td>
<td>31.74</td>
<td>32.58</td>
<td>42.25</td>
<td>36.34</td>
<td>31.55</td>
<td>39.89</td>
</tr>
<tr>
<td>Not important enough</td>
<td>8.45</td>
<td>9.55</td>
<td>8.45</td>
<td>6.46</td>
<td>4.21</td>
<td>15.21</td>
<td>5.92</td>
<td>13.24</td>
<td>24.16</td>
</tr>
<tr>
<td>Not important at all</td>
<td>1.41</td>
<td>1.69</td>
<td>2.54</td>
<td>0.00</td>
<td>0.56</td>
<td>1.41</td>
<td>1.97</td>
<td>0.28</td>
<td>2.82</td>
</tr>
<tr>
<td>Don’t know/ no opinion</td>
<td>3.10</td>
<td>2.81</td>
<td>8.17</td>
<td>1.97</td>
<td>6.74</td>
<td>3.94</td>
<td>4.51</td>
<td>1.69</td>
<td>4.78</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

**Topic 1:** Diagnostic overlap between personality disorder and autism.

**Topic 2:** Gender differences and diagnosis of personality disorder and autism.

**Topic 3:** Is formulation a better approach to treatment decisions than a diagnosis?

**Topic 4:** Improving communication.

**Topic 5:** Crisis support, experiences of being an inpatient.

**Topic 6:** Managing change and uncertainty in everyday life.

**Topic 7:** What helps me? User-led decisions or solutions.

**Topic 8:** This world isn’t made for me – tackling stigma and discrimination.

**Topic 9:** Creativity and improving wellbeing.

These are reported in table two; the most highly rated options were:
We suspected that we might find that people felt lots of topics were important. We, therefore, asked people to choose just one topic as their overall priority for research funding. This time topic three (formulation) was ranked highest, followed by topic one (diagnostic overlap); a full picture is provided in table three.

Table 3: Ranking of topics in order of priority

<table>
<thead>
<tr>
<th>Topic</th>
<th>Rank</th>
<th>% (n=350)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topic 3: Is formulation a better approach to treatment decisions than a diagnosis</td>
<td>1</td>
<td>18.29%</td>
</tr>
<tr>
<td>Topic 1: Diagnostic overlap personality disorder and autism</td>
<td>2</td>
<td>17.71%</td>
</tr>
<tr>
<td>Topic 2: Gender differences and diagnosis in personality disorder and autism</td>
<td>3</td>
<td>13.14%</td>
</tr>
<tr>
<td>Topic 8: Tackling stigma and discrimination</td>
<td>4</td>
<td>12.29%</td>
</tr>
<tr>
<td>Topic 4: Improving communication</td>
<td>5</td>
<td>11.43%</td>
</tr>
<tr>
<td>Topic 5: Crisis support and experience of inpatient</td>
<td>6</td>
<td>8.86%</td>
</tr>
<tr>
<td>Topic 6: Managing change and uncertainty</td>
<td>7</td>
<td>7.71%</td>
</tr>
<tr>
<td>Topic 7: What helps me? User–led decisions or solutions.</td>
<td>8</td>
<td>7.71%</td>
</tr>
<tr>
<td>Topic 9: Creativity and improving wellbeing</td>
<td>9</td>
<td>2.86%</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>100.00%</td>
</tr>
</tbody>
</table>

When we looked at this based on how people identified themselves in terms of service use, the priorities were slightly different (table four).

Table 4: Priorities by service use identification

<table>
<thead>
<tr>
<th>Identify / %</th>
<th>Topic 1</th>
<th>Topic 2</th>
<th>Topic 3</th>
<th>Topic 4</th>
<th>Topic 5</th>
<th>Topic 6</th>
<th>Topic 7</th>
<th>Topic 8</th>
<th>Topic 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism (n=12)</td>
<td>25.00%</td>
<td>8.33%</td>
<td>8.33%</td>
<td>16.67%</td>
<td>8.33%</td>
<td>8.33%</td>
<td>16.67%</td>
<td>8.33%</td>
<td>0.00%</td>
</tr>
<tr>
<td>MH (n=117)</td>
<td>16.24%</td>
<td>15.38%</td>
<td>19.66%</td>
<td>6.84%</td>
<td>7.69%</td>
<td>4.27%</td>
<td>8.55%</td>
<td>17.95%</td>
<td>3.42%</td>
</tr>
<tr>
<td>Both (n=103)</td>
<td>16.50%</td>
<td>19.42%</td>
<td>11.65%</td>
<td>10.68%</td>
<td>9.71%</td>
<td>9.71%</td>
<td>6.80%</td>
<td>11.65%</td>
<td>3.88%</td>
</tr>
<tr>
<td>NA* (n=118)</td>
<td>19.49%</td>
<td>5.93%</td>
<td>23.73%</td>
<td>16.10%</td>
<td>9.32%</td>
<td>9.32%</td>
<td>6.78%</td>
<td>7.63%</td>
<td>1.69%</td>
</tr>
</tbody>
</table>

*NA = not affiliated with service use categories; these included friends/family and those working in the field.

- **Autism**: Rated topic **one** highest, followed equally by four and seven.
- **Mental health**: rated topic **three** highest, followed by eight then one.
- **Both autism and mental health service users**: Rated topic **two** highest, followed by topic one.
- Those without a diagnosis of either chose topic **three** followed by topic one.
This would suggest that one and three were priorities overall. However, the variations between groups is something that requires further discussion and clarification, particularly in light of the low number selecting autism only. What is striking here is how the approach to autism and personality disorder differs, such that formulation is split in terms of its significance to those with different experiences.

This is summarised here by a respondent with a ‘foot in both camps’:

“Please don’t treat autism and PD the same way in the formulation question. Looking at autism from a formulation perspective would be deeply distressing and oppressive to the community, as without a diagnosis we can’t find our tribe. It also carries insinuations of explaining difficulties in terms of life experiences rather than neurology. It’s a really scary idea for autism, despite being sensible for PD.”

These initial findings will be further refined through follow-up conversations with staff, family/friends, and service users, in addition to the comments summarised below.

Additional comments

Existing topics and ideas for further thought

The survey also provided the opportunity for people to add alternative suggestions for topics, or comments on the list provided, with 127 free text responses received. These are summarised by the main themes that emerged through our reading of all the submissions; it is worth noting that communication runs through all of these.

• **Theme one:** The route to diagnosis, including misdiagnosing, and the difference between autism and personality disorder, as well as similarities.

• **Theme two:** Getting the right support in the right place, includes tailoring and psychosocial or adaptive support.

• **Theme three:** Stereotyping and stigma, highlighting the need to raise awareness and increase understanding across services and society. Stigma was common across all themes but also a theme in itself.

Some comments below relate to topics we provided in the survey, whilst others are suggestions which build on these or may lead to different research ideas. What is most evident here is the cross-over between categories that we gave in the survey; these are not discreet and it may be that some topics merge or are revised. We will have to address this when writing the commissioning brief for a research project(s).
In order to access services and other support (theme two) for autism or personality disorder, the first step may be finding the right diagnosis. People related to the ‘diagnosis overlap’ of personality disorder and autism in terms of being misdiagnosed. The negative impact of these experiences was clear.

**Look into misdiagnosis!** Especially as some people with autism can present differently and show higher rates of symptoms such as self-harm and suicidality and relationship problems and emotional dysregulation, but who may then be incorrectly diagnosed with a PD.” Lived experience of both mental health and autism

**Diaragnostically; autism and narcissistic personality disorder are often confused/ misunderstood in staff teams – of course there are very real differences and different ways of working with the presentations. Guidelines for staff on this specific area would be useful.** Staff, working with both

**Supporting people in the mental health system who’ve spent a long time with a PD diagnosis and have suffered iatrogenic harm from not having their autism recognised sooner. There must be thousands of such people (perhaps mostly women) who are viewed as ‘revolving door’ patients because they’ve not had the right support. DO research and select some retrospective case studies for publication to show how this typically ‘presents’.** Lived experience and working with both

An important point is also raised here, that of gender, which may relate to how a diagnosis is reached.

For this parent, lived experience of complex PTSD (often associated with borderline personality disorder) overlapped with those of her child who has an autism diagnosis. Labelling was viewed as a constraint, blinding others to an individual’s strengths, limiting the ability to seek understanding of emotions, experiences and sensitivities.
I am fascinated by how similar our struggle to manage our emotions is. I believe there is a strong overlap that may have to do with sensitivity but also intergenerational trauma...However, it is important that any research in this area is extremely cautious about labelling this sensitivity as a defect. I believe firmly that we can learn to tolerate and regulate our emotions and our sensitivities and intensities can be of benefit to us and the world. Too much emphasis is placed on deficits, research into the strengths that can be utilised to our benefit would help with self-esteem issues and combating stigma and shame. Lived experience and family connection both... What is important here and for others is how early life and coping strategies may look the same but have different underlying mechanisms. This also relates to stigma and stereotyping, inasmuch as expectations emerge from reading a diagnostic label which can limit how individuals are viewed and supported. Taking a formulation based approach could alleviate this, also moving away from the medical model:

More research into alternative ways of describing these difficulties. Moving away from the bio-medical, diagnostic structure. It is all very well to say we still need to use those words ‘personality disorder’ but every time they are used they continue the stigma and discrimination. I applaud your aims but we need to get rid of the label. Lived experience, personality disorder and working with both... However, this was more of a priority for personality disorder and again relates to the stigma of this label. Nonetheless, formulation was seen as beneficial for understanding what is and isn’t helpful on an individual level and as a channel for improving the understanding of ‘risk and risk aversion with regard to the care and treatment of people diagnosed with ASD and/or PD’ (Lived experience, working with both). Through a formulation of needs, identifying the right support would avoid reinforcing negative experiences:

I think it would be good to research experience of talking therapy by autistic people...and maybe also PD. From my own experience, many therapies are counter-productive yet one can get ‘stuck’ in them; psychodynamic therapy in particular does not recognise autistic differences. Formulation that is sensitive to both innate and acquired character may even be an alternative to this. Lived experience, both... Emotional and physical abuse were also cited as experiences by individuals with autism. We were reminded of the consequences of the lack of diagnosis in childhood, by one person explaining experiences of dissociation as a coping response. Dissociation was also reported in people’s experiences of personality disorder. Thus, arguments for and against using diagnosis have been raised, and there appears to be a lean away from this for those who associate with the diagnosis of personality disorder but towards this for autism.
Getting the right support at the right time in the right place

The difficulty of accessing support, particularly person-centred solutions and recognising that not one therapeutic intervention is helpful to all was common across both personality disorder and autism.

“I think services are trying to improve the diagnostic processes and attention has been given to this area but post-diagnostic services have received little attention and can be harmful or non-existent. As more and more people receive a diagnosis we need to offer support early to improve long term outcomes and adjustment to a diagnosis especially if diagnosed as a teenager or adult. Lived experience, both, and family connection

Interventions can be at a very basic level... More help for managing complex social interactions, developing meaningful relationships would be beneficial... focus on better assessment... There needs to be interventions after diagnosis. Work focusing on the waste of resources would be useful, i.e. signposting, holding other services accountable. Lived experience, both, and working with both

Being referred to a service that is not able to meet your needs can be financially and personally damaging; taking a collaborative approach to finding the best support would help to reduce the negative impacts of being signposted to ineffective services. For some it was felt that the support offered was too basic whilst others saw the need to have more help using community resources such as drop-in centres, yoga classes, sensory approaches and better signposting to these. This applied to both personality disorder and autism and may need to take into account co-morbid diagnoses, including eating disorders, depression and anxiety.

A commonality to all was the sensitivity of service users, especially in relating to others, with an insightful suggestion of the link between lack of support and the development of other difficulties:

“I believe some autistics are highly sensitive and they tend to end up with mental health issues like anxiety, depression whilst others are not who tend to end up having issues with aggression. This is just the response to being misunderstood most of the time. Highly sensitive people will simply withdraw and internalise the consequences, less sensitive people will openly show their frustration by becoming angry for example. There is an implication on the management of their autism from early age. Lived experience, autism

Words That Carry On
Thinking more about interpersonal relationships as well as emotions was another common theme for both autism and personality disorder. Responses around understanding health challenges, were linked to comments about accessing support that was based on individual needs and therefore helpful.

Support groups for addictions (gambling, alcohol and substance misuse) were felt to be undervalued; so again, better signposting and a belief that these could provide an additional form of support outside of statutory services was important and frequently minimised.

In addition, people were seen to be too well, being denied access to helpful ongoing psychosocial support which could help to manage the day-to-day difficulties often overlooked by service providers.

“I’d like to see lots of research around what support can be given to those of us who aren’t autistic enough for most autistic services but are clearly autistic enough for diagnosis. Because when exhaustion prevents masking we hit crisis point and get counted as mental health patients but it’s all connected and largely preventable. It has to be cost effective to provide lower level support on a weekly/monthly basis rather than pick up the broken pieces. Lived experience, autism, working and family member”

Short-term interventions during crisis, having access to a GP and being able to find consistent support when needed was essential to wellbeing for both personality disorder and autism. Many found this difficult, especially when seen as ‘managing’ daily life.

Peer support was highly valued in being able to share experiences and reducing isolation, relating to the benefit found in user-led groups and validation:

“Peer mentoring, mutual understanding and a reduction of isolation. Lived experience, personality disorder, working with both”

“I would suggest investigating the impacts of Peer Support (either professionally by Peer Support Specialists, through group therapy, or informal support groups), Dialectical Behavioural Therapy tailored for autism, and the therapeutic relationship between provider and client (I.e. empathy, listening to client needs, unconditional positive regard, consistency, communication style, etc…) Lived experience, both; working with both; family member”

For many, age was an important factor in relation to receiving a diagnosis. Whilst some felt autism was seen more as a childhood label, others found that receiving a diagnosis in adulthood/late life was more problematic due to the lack of support available to older adults.

“Provision of appropriate support for mature adults with diagnoses but who are not in care nor obviously “needy”. They remain remote, lonely and isolated. Lived experience, both; working with both; family member”
More research on gender differences in mature and older adults, barriers in getting a mental health diagnosis, recognition of how depression appears differently in autism, mental health therapists with autism training and therapies adapted to the needs of autistic people and not the one size fits all therapies. Lived experience, both

Therefore, having access to therapies tailored to individual needs which could be provided by clinicians able to work across disciplines, were essential to understanding the commonalities and differences within mental health and autism. This also applied to being adaptive to evolving needs, such that therapeutic interventions matched the timing of this which may vary according to age and previous experience.

Finally, taking a whole-person approach was something that was often missing. The links between mental and physical are well-documented, however are still being overlooked:

Helping the whole person. The interaction between physical and mental health conditions- how to identify these, the possible interplay between them and help people to access the right support. Family member, both

This may be in terms of supporting effective communication of needs when seeking help with a physical health condition, or ensuring that there is a joining up of services (mental health, autism, physical health).

Relating to getting the right support was the setting in which service users were seen. Often this related to not having the support needed earlier in life, continuing throughout adolescence and into adulthood, in some cases leading to contact with forensic services.

A lack of understanding and research into why people become part of this system would be beneficial to both service users and those working in this setting:

Research into the criminal justice system of how many people diagnosed and undiagnosed become victims of this system due to lack of understanding and support, punishment is not the answer, and prison is not a suitable environment for people on the spectrum struggling to cope with life. Lived experience autism, and family connection

Secure environments may also act to replicate and reinforce negative early life experiences. It was, however, recognised by those working in forensic settings that there is a need to understand more to better help people in their care and provide the most beneficial support, for example:

The relationship between cognitive functioning and adaptive behaviour in individuals with autism and/or personality disorder diagnoses. I practice in a forensic personality disorder service; the population has a high level of autistic spectrum traits. It is my (subjective) impression that cognitive deficits, in particular in processing speed, are under-recognised and impact on people’s ability to benefit from interventions, as well as adaptive functioning. Working with personality disorder
This was not just in terms of forensic, but in educational settings:

> Autistic children often feel as if they do not belong in standard school settings due to ostracism, bullying etc. by their peers and/or due to the general set up if the school and attitudes/actions of staff. Research that identifies the degree to which this was a problem and identified factors that increased or decreased the likelihood of autistic children feeling like this would help identify best practice. Furthermore, following up these children as they aged would enable researchers to determine to what extent feeling like they didn’t not belong at school impacted on their adult mental health. Family member, autism

Feeling ostracised resonated with many respondents and across a range of environments. This included schools, hospitals, prisons as well as the navigation of systems such as the Department for Work and Pensions, with individuals feeling ‘dismissed’.

This again related to the overlap between personality disorder and autism, demonstrating the range of settings in which this needs to be addressed.
A number of comments on underdiagnosing both personality disorder and autism in minority groups or by gender were also made, many with reference to stereotyping, bias and stigma. It was felt that there was a “failure to correctly diagnose females from ethnic minority backgrounds” for both personality disorder and autism. Gender was particularly relevant to autism in females and the differences between men and women, for example in relation to hormones. All too-often diagnostic stereotyping was seen to be gender-specific, leading to the following questions:

“Are psychiatrists mis-diagnosing women with a personality disorder when it is actually autism? Lived experience of both”

“I would definitely stress the need for more research on women with autism, and their struggles and needs, given it is only relatively recently that people have begun to look into the very different experiences of autism that women have, compared to men. (I am a woman with an autism diagnosis.)”

“There needs to be research SPECIFICALLY about how women/people who are not men have been previously misdiagnosed with borderline personality disorder when they actually are autistic. I have heard numerous accounts from other autistic women online about their horrible experiences in the mental health system, either being misdiagnosed with borderline personality disorder or bipolar disorder. The idea that borderline personality disorder is a “woman’s” disorder is hugely problematic, and the same goes for the idea that autism is a “man’s” disorder. Women should ALWAYS be assessed for autism before a borderline personality disorder diagnosis is given. Other experience and connections”

Whilst most of the gender comments related to females, and the absence of understanding female autism when a personality disorder was given (especially emotionally unstable personality disorder), there was also a need to recognise autism in males, for example the “prevalence of ASD traits in men diagnosed with antisocial personality disorder”.

There were a number of similar suggestions pertaining to access to training and a multi-disciplinary approach for staff. As shown by the quantitative data, many service users also work in the field and experienced stigmatising attitudes first-hand. This again would be alleviated through improved awareness and understanding through training:
I feel that we need more training and understanding of both of these topics. I live everyday with the discrimination and misconceptions of having a diagnosis of EUPD and DID [dissociative identity disorder]. I now work as a band 6 member of the health service so for me it's of urgent and vital importance to have more research and data to evidence the damage that stigma and lack of understanding and knowledge cause to people like me and the other people in our care that it hurts. Lived experience, personality disorder; working with both

The response of those working in the Criminal Justice system was often felt to be stigmatising and the need for training in front-line and secure settings was central to improving interactions with staff.

Stigma was raised as a concern in relation to society's inability to respond to individual needs, and the response to the label of personality disorder from the public and from services. Also, the need to normalise what society often views as difference through education and challenging language:

Research into different terms for conditions that would help remove some of the stigma and help the general public understand that there is not always a harsh and permanent line between being ‘normal’ and having a diagnosis.

One final comment related to the disparity between how a service should respond and how they may reinforce self-stigma through trivialising or locating the ‘disorder’ within the person:

Yes, something around what many people see as the two-tier mental health service and stigma by professionals about a PD diagnosis. By this, I mean that people are often made to feel that a PD diagnosis isn’t serious/is somehow less worthy of treatment/is about the person being difficult in comparison to other MH diagnoses that are more well-known about such as bipolar disorder. I must state I don’t mean that the latter is not serious, or that this should be a competition for resources, but there seems to be a difference in attitude in services and from professionals and it has a massive impact on access to those services, based on diagnosis and not on the actual experience/level of need/issues that need addressing. Lived experience, personality disorder

Thus, looking at how best to describe the difficulties faced by individuals may be a way forward to removing the stigma that many individuals face. However, this may be more applicable to personality disorder than autism so should be kept in mind.

Nonetheless, a key point in this was that respondents with both autism and/or personality disorder diagnoses found that the relying solely on a medical model was often unhelpful to them, leading to pharmacological rather than psychosocial interventions. From this it may be that in taking a holistic approach, individuals could be better supported through consideration of areas such as neurological development, genetics, early life experiences and the environment. We are aware that there is no one size fits all answer, but equally aware that there are themes that cross both autism and personality disorder, whether this be in terms of difference or similarities.
Conclusions and next steps

From the survey topics it is clear that there are a number of areas that are important to all, with formulation and the diagnostic overlap (especially relevant to females) being rated the highest when ranked in order of preference. The qualitative data adds support to this with the most frequently cited comments being around developing a clear understanding of needs and accessing the right support.

It’s apparent that the identified topics are inter-related insomuch as stigma and discrimination along with improving communication can be integral to understanding the difficulties of individuals seeking support for autism and/or personality disorder. The aspect of discrimination can be in terms of stereotyping by age, gender or ethnicity; it may also be discrimination in relation to the disparity between autism and mental health when looking at diagnosing and access to the right support.

These conclusions are based on the data provided to us and is open for further discussion. We want to ensure that the funds we have raised are put to the best use. To do this, we will be speaking to people and holding workshops.

We would like to thank all of you for your contributions so far, and will be keeping in touch with those who provided contact details. If you have not already given us your permission to keep in touch you can do so my emailing contact@wordsthatcarryon.org.

The next steps are to run workshops for those with lived experience and those working in the field of autism and/or personality disorder. We aim to hold these in September of this year, with about twenty attendees representing a balance of perspectives and experiences. Following this we will be able to refine the purpose of the research, ensuring that the fund is allocated to research that can be applied and will be a lasting legacy to Lindsay.
We understand that the experience of people given a diagnosis of autism, personality disorder or both can be very similar, in terms of how people experience the world and with subsequent behaviours commonly being misunderstood. However, there are also significant differences in the way that people are diagnosed and the type of support given. We need to understand more about the diagnostic process, the overlap between these diagnoses and the impact on providing appropriate support. This topic would also include making recommendations from work on diagnosis on how to improve clinical practice.

We understand that, for some people, there can be uncertainty surrounding diagnosis, with people often receiving a number of different diagnoses over the course of a lifetime. Gender-Based distinctions have received attention in autism (more men are given this diagnosis) and for example an emotionally unstable personality disorder (more women are given this diagnosis). We need to know more about these differences and how they impact on treatment pathways, experiences of support, how diagnostic scales are used in practice and relationship to trauma experiences. This topic would make recommendations on how these gender differences in rates of diagnosis can be addressed to improve peoples’ experience.

Most commonly, an individual is given a diagnosis and this determines the type of treatment or support offered. However, this is considered problematic by many and not all treatments lead to the expected benefits so there is work ongoing across the sector exploring different ways of making treatment decisions. A formulation approach creates a narrative of life experience to help make sense of difficulties and usually involves a psychologist, and potentially family and friends where appropriate. A formulation approach (trauma informed, psychological informed) was recommended in the recent personality disorder consensus statement. What might treatment differences and similarities look like for people given a diagnosis of personality disorder or autism under a formulation compared to a diagnostic approach? Is a formulation approach more acceptable and directly useful to people living with these conditions? This topic would explore the pros and cons of a formulation approach, and make approach recommendations based upon findings.

Appendix one: Survey topics
**Topic 4: Improving communication**

We know good communication underpins positive experience of health and social care for everyone, but particularly people are given a diagnosis of autism and/or personality disorder. However, lack of continuity of care, services’ poor engagement with families and friends, under resourced (and understaffed) services, lack of staff training in nonverbal communication techniques all work against good communication (including listening) in practice. How would people’s experience of support be improved if the ‘communication problem’ was addressed in services (NHS, voluntary sector, private)? This topic would make recommendations for developing communication in and across service settings, highlighting specific communication needs of people with these diagnoses, and for improving the careful, timely and appropriate sharing of information to benefit people using services related to autism or personality disorder and their families.

**Topic 5: Crisis support, experiences of being an inpatient**

Being admitted to a psychiatric hospital is a common experience for many people given a diagnosis of personality disorder or autism (usually due to a dual diagnosis). We know from many years of campaigning by the sector that crisis care is a key priority for many, with strong support for alternative models and approaches. We are particularly interested in comparing people’s experience of inpatient admission to alternative provision including (but not limited to) crisis houses, therapeutic communities and home treatment teams. We want to know how crisis care can be improved to specifically meet the needs of people given a diagnosis of personality disorder or autism. This topic could make recommendations that benefit the wider mental health sector as well.

**Topic 6: Managing change and uncertainty in everyday life**

Dealing with uncertainty in everyday life is difficult for many people, and it can be particularly challenging for people managing problems relating to a diagnosis of personality disorder or autism. We want to know how people given a diagnosis want to address the management of change and make recommendations for achieving better holistic care in practice. This could include addressing consistency of care and managing changes to the services in thoughtful, informed ways as well as exploring coping strategies to help people deal with unexpected change in life in general. It would also help develop further work on the therapeutic value of structure and routine for people with a diagnosis of personality disorder or autism.

**Topic 7: What helps me? User-led decisions or solutions**

The principle of ‘nothing about me without me’ championed by the disability rights movement is centred on the meaningful involvement of people with lived experience at all levels of service design and delivery. Involvement has been enshrined in legislation and evolved significantly with shared decision making and collaborative models of care emerging alongside user-led initiatives. This is of particular importance to people given a diagnosis of personality disorder or autism, who may find commonly used involvement methods inaccessible. We need to know a lot more about user-led care and expertise born out of personal experience (experiential knowledge and expertise) in healthcare delivery (alongside clinical and scientific expertise). What is user-led care in this context? Does it improve outcomes, and how? What best enables people to find solutions for themselves? What input do families and staff need to feel comfortable with, and best able to support this process? This topic could contribute to an emerging evidence base on peer-led interventions.
Topic 8: This world isn’t made for me – tackling stigma and discrimination

Living with autism or personality disorder or both means living with the challenge of managing both the condition itself and the considerable stigma it attracts. Stigma and discrimination associated with autism and mental health are the subjects of international public health campaigns. But few of these campaigns really tackle autism or personality disorder specifically. We need to know more about how we support the public, employers, friends and family and other key parts of society to be more inclusive in their approach.

Alongside this, how can people be best supported to develop coping mechanisms to manage everyday experiences of feeling different, and thinking differently? What skills are needed to build individual resilience thus reducing the impact of public stigma and self-stigma? This topic could contribute to the growing evidence base on stigma research and strategies to increase public awareness.

Topic 9: Creativity and improving wellbeing

The creative talents and interests of people living with autism, personality disorder and other mental health issues can also provide ideas for strategies on how to support others managing similar experiences. People with lived experience, providers and researchers express interest in creativity and mental health, creativity and autism but research in this area is not well developed.

There is not a strong evidence base, for the outcomes that may result from harnessing creativity in communication or in strategies for support and management of health issues. Thus, projects focused on creativity may struggle to access funding.

We are interested in exploring how creativity can be facilitated to help people manage distress and explore trauma experiences on their own or alongside other supports. This research topic would contribute to the broadening of the evidence base.

Author information and acknowledgements

This report was written by Jennie Parker, drawing upon lived experience of personality disorder and conversations with Lindsay’s friends, family, and clinicians. Thank you to all who completed the survey and contributed through discussions, we hope these have all been represented in the above summary.
About the McPin Foundation

We are a mental health research charity. We champion experts by experience in research so that people’s mental health is improved in communities everywhere.

- We deliver high-quality, user-focused mental health research and evaluations
- We support and help to shape the research of others, often advising on patient and public involvement strategies
- We work to ensure research achieves positive change

Research matters because we need to know a lot more about what works to improve the lives of people with mental health difficulties, their families and communities. We believe better mental health research is done by involving experts by experience. We work collaboratively with others sharing our values.

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