Appendix 3: Top three factors linked with supporting a person to live their best life from the Whole Life Disability and Neurodiversity Strategy survey (January 2023) for children and adults

| Rank                                     | Factors mentioned by survey responders as being most important to them   | Emerging priorities linking to these (see paragraph 10 of the Health and Wellbeing Board report)  |
|--|--|---|
| 1 for                                    | Family, friends, and relationships   |   |
| adults 3 for children and young people   | <ul> <li>Importance of these identified by responders were around:</li> <li>Love and intimacy</li> <li>Care and support 'through good and bad times'</li> <li>Giving people 'a voice' and advocacy and 'fighting for them'</li> <li>Confidence</li> <li>Happiness</li> <li>Safety and security</li> <li>Supporting mental health</li> <li>Reducing social isolation</li> </ul>   | 5. Where people need care and support, make sure that support considers the whole person's needs, what they want to achieve and what people can do. It should not interfere with their life.  |
| 2 for                                    | Access to health and social care, shops, and other services  |   |
| adults  12 for children and young people | Access to health and social care, shops, and other services  Access to health services, but also to social care support were the most commonly mentioned factors for this group. Where specific mention was made of services, mental health support was the most commonly mentioned factor. Access to other specific support that people required was mentioned, including:  • Epilepsy support  • Families having time out / respite from caring  • Access to support using a personal assistant  • Support for rare neurodegenerative conditions  • Community nursing team support for neurodivergences  • Support and understanding for combinations of needs e.g., Autism with ADHD  • Need for help to book online or using email or text rather than through traditional routes. | <ol> <li>Make Staffordshire more open and inclusive.</li> <li>Build stronger partnerships between local organisations, people, and local communities.</li> <li>Listen and be kind and thoughtful to people's needs. This is so that experiences of day-to-day activities and opportunities can be equal to the experience other people take for granted, where this is possible.</li> <li>Ensure people can be better informed, feel in control of their lives and can live as independent a life as they can.</li> </ol> |

| Rank | Factors mentioned by survey responders as being most important to them   | Emerging priorities linking to these (see paragraph 10 of the Health and Wellbeing Board report)   |
|------|--|--|
|      | <ul> <li>Having a choice of face-to-face appointments (especially for those with a visual or hearing impairment) and virtual appointments (for neurodivergent individuals whereby face to face appointments may make some people feel anxious)</li> <li>Access to speech and language therapy (brain injury related)</li> <li>Access to complementary medicine (e.g., acupuncture) and support for wider needs (such as eating disorders and phobias)</li> <li>Treating the source of pain experienced / pain management support</li> <li>Ensuring support given involves families</li> <li>Long waiting times and delayed diagnosis was mentioned specifically and with a similar frequency to that of mental health support. Some responders did mention a lack of diagnostic services for Autism and ADHD and sourcing this out of county and female autism diagnosis was reported as 'being missed frequently'.</li> <li>Aftercare following diagnosis was another area identified as problematic to access.</li> <li>Access to shops and other services, places of interest and to leisure opportunities were also specifically mentioned to reference their importance.</li> </ul> | 5. Where people need care and support, make sure that support considers the whole person's needs, what they want to achieve and what people can do. It should not interfere with their life. |

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|--|--|--|
| 3 for                                  | Appropriate and safe home  |  |
| adults 7 for children and young people | <ul> <li>The following were particularly noted as important:</li> <li>Comfort</li> <li>Safety and security</li> <li>A calming / emotionally safe and loving place where people can be themselves</li> <li>'My home provides a place to socialise, be part of my community, work and access to a suitable environment to enjoy wider life.'</li> <li>'Living in the right home with the correct level of support'</li> <li>'Kind and knowledgeable staff and a safe environment to allow independence at a level suitable for the individual.'</li> <li>Adaptations' to suit the needs include safety and technology – in this case 'smart houses' was mentioned. However, the ongoing need for the home environment to be adapted in accordance with changing needs was raised by several responders – not just to meet the needs of their disability or neurodivergence, but also to ensure happiness, safety, belonging, and to assist independence with least restriction and to increase confidence and abilities.</li> <li>Accessibility was also mentioned: 'are you where you want to be near a bus route, park, shops, nature'</li> <li>Independence was also mentioned: 'to be self-contained but have easy access to support services if needed.'</li> </ul> | <ol> <li>Build stronger partnerships between local organisations, people, and local communities.</li> <li>Listen and be kind and thoughtful to people's needs. This is so that experiences of day-to-day activities and opportunities can be equal to the experience other people take for granted, where this is possible.</li> <li>Ensure people can be better informed, feel in control of their lives and can live as independent a life as they can.</li> <li>Where people need care and support make sure that support considers the whole person's needs, what they want to achieve and what people can do. It should not interfere with their life.</li> </ol> |

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|---------------------------------|---|--|--|
| 4 for adults                    | Social life / social skills / Getting out and about in local community  |  |  |
| 2 for children and young people | <ul> <li>The following were particularly noted as important:</li> <li>The ability to meet people and make 'true' friends. The need to have help developing social skills to do this or to expand social networks was mentioned by a number of responders</li> <li>To reduce social isolation</li> <li>Meeting other people 'in the same boat' was identified as important for some responders - one example of such was an individual with a spinal cord injury providing support to others with similar injuries and noting how important that was. Other examples were from neurodivergent responders</li> <li>Having opportunities for days out and holidays was mentioned by a number of responders</li> <li>The importance of disability and neurodivergent-friendly opportunities were noted by a large number of responders</li> <li>Some responders cited the importance of 'support workers' or personal assistants to support this</li> <li>The benefits of experiencing new things, having meaningful activities, and enjoying things that matter was also noted. Accessing specific places such as museums and parks and 'the environment' were also mentioned by a number of respondents.</li> </ul> | <ol> <li>Make Staffordshire more open and inclusive.</li> <li>Build stronger partnerships between local organisations, people, and local communities.</li> <li>Listen and be kind and thoughtful to people's needs. This is so that experiences of day-to-day activities and opportunities can be equal to the experience other people take for granted, where this is possible.</li> <li>Ensure people can be better informed, feel in control of their lives and can live as independent a life as they can.</li> <li>Where people need care and support, make sure that support considers the whole person's needs, what they want to achieve and what people can do. It should not interfere with their life.</li> </ol> |  |

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|---|--|--|
| 5 for                                   | Positive educational experience  |  |
| adults  1 for children and young people | <ul> <li>A range of different issues were raised in relation to this:</li> <li>For some, actually being able to attend school was raised</li> <li>A number mentioned attending the right school and having 'the right education'. Views on what was right varied. They included identifying that mainstream schools need to be more inclusive, non-judgemental, needing to work well with parents and having dedicated support staff. Alternatively, many also highlighted the need to mix with children with the same capabilities within a more supportive, therapeutic special school environment.</li> <li>Attainment was raised by a few responders. This included a couple of respondents identifying they wanted to 'learn to read and write'. Accessibility of traditional qualifications was also raised as a concern by some. One responder did mention the importance of academic qualifications alongside learning other skills such as life skills and housekeeping skills.</li> <li>Educational aspiration and wanting to achieve but also a level of apprehension around further and higher education was highlighted.</li> </ul> | <ol> <li>Make Staffordshire more open and inclusive.</li> <li>Build stronger partnerships between local organisations, people, and local communities.</li> <li>Listen and be kind and thoughtful to people's needs. This is so that experiences of day-to-day activities and opportunities can be equal to the experience other people take for granted, where this is possible.</li> <li>Ensure people can be better informed, feel in control of their lives and can live as independent a life as they can.</li> <li>Where people need care and support, make sure that support considers the whole person's needs, what they want to achieve and what people can do. It should not interfere with their life.</li> </ol> |