



## SHEFFIELD NEURODIVERSITY WAITING TIMES PROGRAMME

### SHEFFIELD HEALTH AND CARE PARTNERSHIP BOARD

15 AUGUST 2023

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<b>Sponsor(s)</b>	Sandie Buchan, Director of Strategy, Sheffield Place, NHS South Yorkshire Alexis Chappell, Strategic Director of Adults' Care and Wellbeing, Sheffield City Council Craig Radford, Chief Operating Officer, Sheffield Children's NHSFT Neil Robertson, Director of Operations and Transformation, Sheffield Health and Social Care NHSFT
<b>Purpose of Paper</b>	
To present the HCP Priority Programme Brief for discussion and approval.	
<b>Key Issues</b>	
Risks/Issues (high level) noted in the Programme Brief	
<b>Is your report for Approval/Consideration/Noting</b>	
Sheffield Health and Care Partnership Board is asked to approve the enclosed HCP Priority Programme Brief on Neurodiversity Waiting Times.	
<b>Recommendations/Action Required by the Sheffield Health and Care Partnership Board</b>	
It is recommended that Sheffield HCP Board: <ul style="list-style-type: none"> <li>• Approve the Priority Programme Brief</li> </ul>	
<b>What assurance does this report provide to the Sheffield Health and Care Partnership Board in relations to the ambitions of the Health and Wellbeing Strategy 2019-2024</b>	
	<b>Please</b> ✓
<b>Every child achieves a level of development in their early year for the best start in life</b>	✓
<b>Every child is included in their education and can access their local school</b>	✓
<b>Every child and young person has a successful transition to independence</b>	✓
<b>Everyone has access to a home that supports their health</b>	✓
<b>Everyone has a fulfilling occupation and the resources to support their needs</b>	✓
<b>Everyone can safely walk or cycle in their local area regardless of age or ability</b>	
<b>Everyone has equitable access to care and support shaped around them</b>	✓
<b>Everyone has the level of meaningful social contact that they want</b>	✓
<b>Everyone lives the end of their life with dignity in the place of their choice</b>	



<b>Are there any Resource Implications (including Financial, Staffing etc)?</b>
Yes, these are included in the paper.
<b>Have you carried out an Equality Impact Assessment and is it attached?</b>
An EIA has not been completed at this stage of the programme but will be completed as a priority by project teams as work progresses.
<b>Have you involved patients, carers and the public in the preparation of the report?</b>
CYP and adults, parents and carer engagement involvement has shaped the programmes' aims and objectives. The projects within the programme brief have/are/will include CYP and adults, parent and carer involvement.



## NEURODIVERSITY WAITING TIMES PROGRAMME BRIEF

<p><b>Programme Title</b> To improve the support for people who are neurodiverse, reducing waiting times to access services and ensuring we have appropriate support offers available.</p>	<p><b>Reference No.</b></p>	
<p><b>Place Team and Governance</b></p>	<p>Autism Partnership Board Children and Young People Delivery Group Mental Health, Learning Disabilities and Autism Delivery Group</p>	
<p><b>Place Executive Leads</b></p>	<p>Sandie Buchan, Director of Strategy, Sheffield Place, South Yorkshire Integrated Care Board (SYICB)</p> <p>Alexis Chappell, Strategi Director of Adults’ Care and Wellbeing, Sheffield City Council</p> <p>Craig Radford, Chief Operating Officer, Sheffield Children’s NHSFT</p> <p>Neil Robertson, Director of Operations and Transformation, Sheffield Health and Social Care NHSFT</p>	
<p><b>Project Leads</b></p>	<p>Kate Gleave, Deputy Director, Children and Young People and Urgent Care, Sheffield Place, SYICB</p> <p>Heather Burns, Deputy Director, Mental Health Transformation, Sheffield Place, SYICB</p> <p>David Newman, Consultant Clinical Psychologist, Sheffield Health and Social Care NHSFT</p> <p>Sal Foulkes, Service Manager, Sheffield Health and Social Care NHSFT</p> <p>Chris Hayden, Deputy Chief Operating Officer, Sheffield Children’s NHSFT</p> <p>Rachel Dillon, Strategic Programme Manager, Sheffield Place, SYICB</p> <p>Raheel Baig, Commissioning Manager, SCC and Sheffield Place, SYICB</p>	
<p><b>Clinical &amp; Professional Lead</b></p>	<p>Anthony Gore, Clinical Director, CYP, Sheffield Place.</p> <p>Jonathan Mitchell, Associate Clinical Director, Sheffield Health and Social Care NHSFT</p> <p>David Newman, Consultant Clinical Psychologist, Sheffield Health and Social Care NHSFT</p> <p>Further Clinical and Professional Leads to be confirmed.</p>	
<p><b>Programme Aims</b></p>	<p>This brief describes high level what we as a partnership plan to do to help address waiting times in Autism and ADHD. It’s 1 of 5 priorities for the HCP and is an All Age Autism strategy priority.</p> <p>It should be read in conjunction with the All Age Autism three year strategy as this sets out our broad strategic aims and commitments. This plan will contribute in delivery of aims 1,2, and 4 of the Strategy. <sup>1</sup></p> <p><b>Our aim is to design an approach in Sheffield to:</b></p> <ul style="list-style-type: none"> <li>• support and meet the needs of neurodivergent children, young people, adults and their families, first time in a more holistic way,</li> <li>• move away from a medical centric service (where appropriate) to one which supports and empowers people in their communities.</li> <li>• alleviate pressure on the current specialist model of care for Autism and ADHD.</li> <li>• improve current routes for assessment and follow up.</li> </ul> <p>This will require a cultural and system change in which the impacts will take longer than this brief to embed. This delivery plan starts to describe the key steps to putting plans in place by September 2024. Key milestones are described in the milestones section below.</p>	



		<p>We will be involving people with lived experience and their parents and carers to co-design this approach.</p> <p>In addition, this requires all partners to participate and lead including health, education, voluntary sector, employment, and children and adult services.</p>			
<b>Rationale</b>		<ul style="list-style-type: none"> <li>• Sheffield coproduced All Age Autism Strategy has recently been agreed.</li> <li>• Sheffield Safeguarding Partnership raised autism waiting times as a risk within the city.</li> <li>• Nationally, waiting lists for Autism and ADHD assessments for all age have increased considerably over the last 3 years. National CYP ADHD average wait for an assessment is 104 weeks.</li> <li>• Increased awareness of autism and ADHD has significantly increased referral rates within Sheffield and nationally and has increased demand on all our statutory services including Schools and Social care.</li> <li>• Increased medicalisation of autism and ADHD.</li> <li>• Sheffield Children’s FT Neurodisability service has seen a doubling of referrals from 2018/19 to 2022/23 and people are waiting up to two years for an assessment. Current waiting times to be seen as at March 2023:             <ul style="list-style-type: none"> <li>○ 69 weeks for preschool autism (477 waiting)</li> <li>○ 71 weeks for ADHD assessment (420 waiting). Anticipated RTT standard will be breached August and September.</li> <li>○ 102 weeks for school age autism assessment (973 waiting)</li> </ul> </li> <li>• A further @2000 patients in the system awaiting parent/carers and/or school questionnaires.</li> <li>• Significant additional investment in new posts has already taken place (£800k), however demand still outstrips capacity.</li> <li>• For adults collectively for autism and ADHD, waiting times have increased since the pandemic, particularly for ADHD, and the average waiting time is 81.8 weeks, with 7735 on the waiting list as at May 2023, across Sheffield, NE Derbyshire.</li> <li>• There are major challenges in recruitment and retention in both CYP and Adults clinical services.</li> <li>• CYP families and adults have told us that they do not receive appropriate support to meet their needs, pre and post diagnosis, and they wait too long to obtain an assessment. This impacts on all areas of their life, employment, school attainment and mental wellbeing.</li> <li>• For many people, the only perceived or actual way to gain support is through a diagnosis, for others, diagnosis is crucial for their validation.</li> </ul>			
<b>Programme Time Frame</b>					
<b>Start date</b>	Started	<b>End date</b>	September 2024. However, it will take longer than this to see the impacts of this large-scale change. (This delivery plan is in conjunction with the All-Age Autism	<b>Review period</b>	Through the two Delivery Groups monthly.



Strategy 2023-2026)			
Project Team	Role	Time Commitment	Oversight
Autism Partnership Board. New governance arrangements via workstreams to deliver Autism Strategy priorities.  Currently for CYP: CYP Neurodevelopment Transformation Task & Finish Group	Management of delivery of this priority	Monthly  Fortnightly	All Age Autism Partnership Board CYP Delivery Group Mental Health, Learning Disabilities, Dementia and Autism Delivery Group
Programme Objectives			
<p><b>Overall Objectives (using All Age Autism Strategy and existing programmes as framework)</b></p> <ul style="list-style-type: none"> <li>Working collaboratively with people with lived experience, develop a holistic approach of support and empowerment, to meet the needs of CYP and Adults and their families/carers first time with the right support.</li> <li>Improve awareness raising, skills and training through delivery of high-quality training about autism and ADHD across all statutory frontline services.</li> <li>Significantly improve the public's understanding and acceptance of autism and ADHD.</li> <li>Inform frontline staff, young people and adults and their families and carers how to identify and support neurodiverse needs.</li> <li>Ensure all schools provide neurodiverse accessible environments by improving the sensory environment with commitment and improved awareness and acceptance from all school leaders.</li> <li>Develop training materials for health, education, and care staff to ensure that each child's individual special education needs are understood and met, they are supported to attend school and prepared for a smooth transition to adulthood.</li> <li>Ensure that there is help for everyone to understand autism and ADHD, throughout the wider community and in education settings from nursery school age onwards.</li> <li>Improve access to support for all people based on need and not assessment.</li> <li>When assessment is required, improve the diagnosis pathway, so that CYP and Adults have a better experience.</li> </ul> <p>These have been informed by significant engagement with neurodiverse people and their families and delivery will continue to be coproduced with neurodiverse people and their families.</p>			
Programme Scope			
Project scope – In		Project Scope – Out	
<ul style="list-style-type: none"> <li>All Age</li> <li>Autism needs and ADHD needs</li> </ul> <p>The main focus within this project brief is Autism and ADHD. However, there are a core set of needs we are not consistently meeting in the city within neurodiversity, such as behaviour, sleep, anxiety, emotional wellbeing, mental health, which all people and their families need support with, with or without a diagnosis. Therefore, where we have objectives which done once and meet all needs prove more efficient, we will deliver to cover all neurodiverse needs.</p> <p>This is not just a health problem, to ensure we meet the needs and reduce the demand of specialist statutory services we need our transformation response to include:</p>		<ul style="list-style-type: none"> <li>Inclusion (working under the Inclusion Board and SEND related programmes)</li> <li>Eating Disorders (which is looking at Avoidant/Restrictive Food Intake Disorder (ARFID) which can be related to Autism).</li> <li>National LDA programme (formerly Transforming Care which will focus on reducing access to avoidable inpatient care)</li> </ul>	



<ul style="list-style-type: none"> <li>All Age Autism Strategy workstreams</li> <li>Voluntary Sector</li> <li>Parenting support and School Autism Team</li> <li>0 – 19 service</li> <li>Health Inclusion Team – Health Visitors for Asylum Seekers/Travellers</li> <li>Adults and Childrens Mental Health services</li> <li>Child Services</li> <li>Early years childcare and education providers</li> <li>Schools – mainstream primary and secondary school</li> <li>Universities and Colleges</li> <li>Domestic Abuse Refuges</li> <li>Access to suitable housing</li> <li>Access to employment</li> <li>Justice System</li> </ul>		<ul style="list-style-type: none"> <li>“Greenlight Working protocols” on improving access to generic mental health care</li> </ul> <p>All of these are co-dependencies but not in project scope</p>	
Benefits	Impact/Outcomes (over the life of the All Age Autism Strategy)	Measurements	Stakeholder
<ul style="list-style-type: none"> <li>Improved frontline staff’s confidence in signposting, supporting and having conversations with neurodiverse people and their families with neurodiverse needs via national and citywide training packages.</li> <li>Early identification and timely support will be provided to better meet the needs including early years and early intervention.</li> </ul>	<ul style="list-style-type: none"> <li>Staff have a better understanding of neurodiverse CYP’s and adult’s needs and how to talk to families about this.</li> <li>Reduction in inappropriate contacts to the specialist services.</li> </ul>	<p>Pre and post training measurements and formal evaluation of new local training.</p> <p>Audit of contacts to specialist services.</p>	<p>CYP and adults Families Staff</p>
<ul style="list-style-type: none"> <li>Improved access to universal support delivered in the community without a diagnosis, introducing an approach to meet need with the most appropriate, holistic support and personalised care.</li> <li>A more holistic model of support delivered together and consistently by all partners in Sheffield</li> <li>Nurseries, Schools and Colleges feel more empowered to support their pupils/students.</li> </ul>	<ul style="list-style-type: none"> <li>Increased commissioning of VCSE services for support, for neurodevelopment people and their families, building on progress to date to alleviate pressures on statutory services.</li> <li>Improved patient outcomes for those with co-morbidities</li> <li>Reduction in referrals requested in order to obtain support to meet need.</li> <li>People and their families feel more satisfied that their needs are being met holistically.</li> <li>Impact on waiting times will become evident beyond 2024.</li> </ul>	<p>Count of support services available without a diagnosis</p> <p>City wide and community questionnaire.</p>	<p>CYP and adults Families Staff VCSE</p>
<ul style="list-style-type: none"> <li>An increase in the number of schools who have made their environments more neurodiverse friendly.</li> </ul>	<ul style="list-style-type: none"> <li>Neurodiverse young pupils feel more comfortable in school with increase in school attendance and reduction in exclusions.</li> <li>Parents and Carers feel more satisfied with their experience.</li> </ul>	<p>Formal evaluation of Autism in Schools project.</p>	<p>CYP Families Staff</p>



<ul style="list-style-type: none"> <li>More clinical staff are in place in clinical services.</li> </ul>	<ul style="list-style-type: none"> <li>A reduction in Paediatric waiting times for autism assessment from 78 weeks in July 23 to below 65 weeks by March 2024. <sup>2</sup></li> <li>Parents and Carers feel more satisfied with their experience</li> </ul>	Waiting time numbers.	CYP and Adults Families Staff
<ul style="list-style-type: none"> <li>Continued improvement of assessment pathway in Adult autism service.</li> </ul>	<ul style="list-style-type: none"> <li>A reduction in waiting times for Sheffield adult autism assessment from 70 weeks in July 23 to below 65 weeks by March 2024. <sup>3</sup></li> </ul>	Waiting time numbers.	Adults Families Staff
<ul style="list-style-type: none"> <li>Reduction in paediatric ADHD follow up backlog</li> <li>Plans are for capacity to increase from October as part of SCFT Investment. However, this is dependent upon there being sufficient follow up capacity to ensure patients are managed on ADHD drugs appropriately. (HIGH RISK see risk section below)</li> </ul>	<ul style="list-style-type: none"> <li>Adults and families will have an improved experience in follow up.</li> <li>Specific metrics and trajectories are still being worked up for waiting times reductions for this measure.</li> </ul>	Follow up numbers	CYP Families Staff
<ul style="list-style-type: none"> <li>Review of adult ADHD pathways will inform an alternative community support provision to align assessment and diagnosis into a tiered system supported in primary and secondary care mental health.</li> </ul>	<ul style="list-style-type: none"> <li>Adults and their families and carers will wait less for an assessment. Impact may not take affect until after March 2024.</li> <li>Adults and their carers will be able to access support closer to their home.</li> </ul>	Waiting time numbers in the long term.	Adults Families Staff
<ul style="list-style-type: none"> <li>Improved transition between CYP and Adult services in the hospitals assessment processes.</li> </ul>	<ul style="list-style-type: none"> <li>Young People 16-18 will have an improved experience transitioning between CYP and Adults services.</li> </ul>	Citywide questionnaire (although no current baseline to use)	Young People Families Staff
<ul style="list-style-type: none"> <li>All programmes of improvement and change have been co-developed with parents and carers and those with lived experience.</li> </ul>	<ul style="list-style-type: none"> <li>Parents and carers and those with lived experience have codesigned new programmes.</li> </ul>	Through regular programme and project monitoring.	Young People Families Staff

<sup>2</sup> assuming demand for statutory services stays the same or reduces

<sup>3</sup> providing workforce model is stable

High Level Milestones	Implementation
<b>Children and Young People Milestones</b>	
Gain a common understanding across South Yorkshire, Academic Health Science Network and nationally of: <ul style="list-style-type: none"> <li>current practice and evidence of meeting need first time through a social model and;</li> <li>referral process with a view to exploring alternative pathways, ensuring high level and quality referrals are received.</li> </ul>	<ul style="list-style-type: none"> <li>November 2023</li> </ul>
Based on above, improve access to support based on need to empower and support CYP, adults, families and frontline staff:	<ul style="list-style-type: none"> <li>July 2024</li> </ul>



<ul style="list-style-type: none"> <li>Negotiate if barriers/referral criteria can be removed.</li> <li>Improve access to universal support</li> </ul>	
Based on above, deliver new approach to meeting need first time	<ul style="list-style-type: none"> <li>September 2024</li> </ul>
Additional £800k of staffing into Neurodisability services. This will help meet some of the rising demand but will not significantly reduce the waiting times.	<ul style="list-style-type: none"> <li>September 2023</li> </ul>
Autism in Schools <ul style="list-style-type: none"> <li>secure funding to continue to roll out project to more schools</li> </ul>	<ul style="list-style-type: none"> <li>September 2023</li> </ul>
To roll out Inclusion Model across four school localities to enhance support for neurodiverse CYP.	<ul style="list-style-type: none"> <li>TBC</li> </ul>
To increase peer support for parents and carers through 1-1s, information sessions and peer support groups across Sheffield and into specific communities.	<ul style="list-style-type: none"> <li>Ongoing</li> </ul>
Secure funding to improve access to ADHD support for families via new model of care.	<ul style="list-style-type: none"> <li>October 2023</li> </ul>
Review options around the independent sector on provision.	<ul style="list-style-type: none"> <li>TBC</li> </ul>
<b>Adult Specific Milestones</b>	
Development of a drop-in support service for Adult Autism Support <ul style="list-style-type: none"> <li>Procure service</li> <li>Mobilisation</li> <li>Go live</li> </ul>	<ul style="list-style-type: none"> <li>December 2023</li> </ul>
VCS led Adult Autism diagnosis Waiting List project	<ul style="list-style-type: none"> <li>December 2023</li> </ul>
To review alternative approaches to Adult ADHD assessment, diagnosis and support through working with the 2 University practices, where 40% of referrals into ADHD patient choice providers originates, looking at a tiered pathway across primary and secondary care.	<ul style="list-style-type: none"> <li>January 2024</li> </ul>
To improve crisis response to adults with autism through the development of a lead nurse for crisis to act as an interface with the adult autism service and the Home Treatment/Adult Teams	<ul style="list-style-type: none"> <li>In post by October 2023</li> </ul>
<b>CYP and Adult Milestones</b>	
Deliver Communications Campaign to increase understanding and awareness	<ul style="list-style-type: none"> <li>July 2024</li> </ul>
Training For All Frontline Staff on Autism and ADHD (National and locally coproduced) and deliver a citywide approach to ensure consistency for our service users.	<ul style="list-style-type: none"> <li>August 2024</li> </ul>
Review SCFT and SHSC and primary care assessment pathways on transition of patients	<ul style="list-style-type: none"> <li>December 2023</li> </ul>
<b>Additional Resource Required</b>	
Assumes existing teams/services will contribute clinical and managerial leadership/input into delivery of programme.	
<p>Identified</p> <ul style="list-style-type: none"> <li>1 WTE paediatric Project Manager (Post filled from Oct 23 but funded and vacant until that point)</li> <li>Band 8 adult nursing post identified through Strategic Development Funding (SDF)</li> <li>Autism Support Hub identified through SDF funding</li> </ul> <p>Not Identified</p> <ul style="list-style-type: none"> <li>0.5 WTE Project Manager (Band 7) to support delivery of paediatric projects</li> <li>£30k for Adult and CYP comms and marketing campaign</li> <li>£100k Funding for Autism in Schools continuation</li> <li>Discussion required at system level around private sector capacity for CYP Autism assessments</li> <li>6 WTE Administration for CYP Single Point of Access.</li> </ul>	





- Further clinical investment is required into paediatric ADHD services. Staffing requirements will be known once urgent review has taken place.
- Potential investment in 2024/25 against prioritisation programme for adult Autism/ADHD, dependent on the model implemented to alleviate pressure on specialist service.
- Additional support into new model of community provision for CYP ADHD with and without assessment £173,716\* per year (pending pay award)

**Finance** (please provide high level estimates at this stage)

£0,000	FY 23/24	FY 24/25	Ease of Implementation High/Medium/Low
<b>Estimated Investment</b>			
<b>Gross Savings</b>			
<b>Total Net Savings</b>			
<b>Cash Releasing/Cost Avoidance</b>			As a system we recognise the need to quantify this and are currently working on how we do this. Once we review evidence and learning from other areas on a new approach, we will be able to quantify this in more detail. If we reduce waiting times and increase support, overtime we should see a reduction in need for example special school places, school staff should spend less time dealing with crisis, attendance should improve, less exclusions, less adults CYP their parents and carers in MH ill health or emotional crisis and there may also be a reduction in admissions to Tier 3 Provider Collaborative beds for CYP and into adult inpatient beds.

**Interdependencies**

- Sheffield All Age Autism Strategy
- CYP Mental Health
- Mental Health Crisis Transformation Programme
- Inclusion Strategy
- Implementation aspects of the MH strategy and MHLDDA priorities for 23/24
- Physical Health Strategy
- Foetal Alcohol Spectrum Disorder (FASD) Programme
- Speech and Language Therapy Transformation Programme
- South Yorkshire MHLDA Provider Collaborative
- South Yorkshire wide Suicide Prevention for Autism
- Education including SENCOS
- National Learning Disability/Autism Programme (formerly Transforming Care)
- Discharge Planning/Admissions avoidance
- Eating Disorders (CYP and Adults) in particular Avoidant/Restrictive Food Intake Disorder pathways
- Improve access to generic primary, secondary and generic health care to help to address health inequalities for this population.

**Risks**

Risks	Mitigation
1. Tension between deploying limited workforce to undertake additional assessments or improve support to meet needs (and reduce demand)	1. Focus on pathway redesign and potential private capacity in Autism where pathway is not as complex as ADHD. Agreement needed that if focus is on demand management and patient family /resource this will have an impact on waiting times for the short to medium term.





<ol style="list-style-type: none"> <li>2. Tension in ADHD between initial assessments and ensuring enough follow up capacity to ensure that patients are adequately managed on ADHD medication.</li> <li>3. Delivery of the impacts will require behavioural change from all parts of the system.</li> <li>4. Additional investment within SCFT on £800K addresses Autism waits only at this point and delivers waits of below 65 weeks <b>only</b> until the end of 2024. This is due to demand outstripping additional capacity and length of time additional support and demand management strategies will take to put in place.</li> <li>5. No additional capacity has been factored into Autism as the level of investment will only allow us to address ADHD waits which are more urgent due to the follow up review pathway for those patients on medication.</li> <li>6. Risks associated with increased referrals via Patient Choice through increased social media focus and the turnover of new students arriving in Sheffield each year at 2 universities. Currently 40% of referrals through this route come from the 2 University practices.</li> <li>7. Recruitment and retention of skilled staff due to pay rates in private sector agencies who are proliferating in the assessment of ADHD and autism and who pay higher rates on pay than the NHS</li> <li>8. CYP Autism and ADHD services in Sheffield are currently commissioned by NHS England which means contractually the ICB has limited opportunities.</li> </ol>	<ol style="list-style-type: none"> <li>2. Modelling being undertaken with SCFT to understand impact of flexing between new and follow up (FU) capacity in ADHD. Slippage in assessment investment to be focused on ADHD FU.</li> <li>3. Work as system representatives to take ownership of the objectives and coproduce impact deliverables.</li> <li>4. Discussion required within ICB on current resource within system and potential for private sector investment versus investment in substantive NHS services.</li> <li>5. System level focus on demand management and support for patients/families in this area. See milestones above which sets out high level plan.</li> <li>6. Work to start to review adult ADHD tiered pathway across primary and secondary care.  Communications Campaign to increase awareness and support available for people.</li> <li>7. To work towards implementing benefits which will improve staff experience locally.</li> <li>8. The ICB is in discussion with NHS England about the transfer of the contract to the ICB.</li> </ol>
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**Supporting Information**

<sup>1</sup> Sheffield All Age Autism Strategy 2023-2026: Year One Priorities  
[PowerPoint Presentation \(sheffield.gov.uk\)](https://www.sheffield.gov.uk)

