Appendix 2

Your LINk for improving health and social care

the KENT LINk
a LOCAL INVOLVEMENT NETWORK

22 December 2010

Paul Wickenden
Overview, Scrutiny and Localism Manager
Kent County Council
Sessions House
County Hall
County Road
Maidstone ME14 1XQ

Dear Mr Wickenden

The Kent LINk has been asked to take up the issue that an insufficient service is being provided by the Child and Adolescent Mental Health Services (CAMHS), particularly for children with Autistic Spectrum Disorder (ASD).

We have been informed that back in March 2010, 324 children in Shepway were on the paediatric database having been diagnosed with ASD by the paediatric team. This figure does not include those diagnosed separately by CAMHS staff. Effective help needs to be available for these children. Shepway CAMHS is said to have only three staff not the sixteen they need. The group has reported constant problems with cancellation of appointments, due to lack of staff. During further investigation the lack of staff is said to be a problem throughout Kent.

Parents have reported the following issues:

- Long waiting lists, for example a year or more for initial assessment
- No crisis intervention for children with suicidal tendencies or self harming behaviour
- Lack of alternative therapies; for example Cognitive Behaviour Therapy, family or group therapy, small groups, sibling therapy or parenting programmes
- The service provision for Shepway is different to that which is provided for relatively local areas such as Dover, Canterbury and Ashford. These do not seem to have long waiting lists like those in Shepway
- Lack of multi-disciplinary collaboration between service providers such as speech and language therapists, occupational therapy and paediatricians
- There is a need for CAMHS staff to be able to offer outreach into schools so they can be involved in observing the children in the classroom setting
- CAMHS have refused to be involved with pupils who have mental health issues, leaving no other service available to parents

- CAMHS does not offer any help on an emergency / crisis basis where there is violence by an ASD child to siblings or parents.

It appears that the lack of Tier 2 provision for young people (family and therapeutic support) has resulted in cases being escalated into Tier 3, (crisis intervention) and therefore, causing a failing to young people and their families.

This issue was first brought to the Priorities Panel in March 2010 and was put on hold while Canterbury Christ Church University, as part of the CAMHS Pathway Project, completed their research project into CAMHS. The researchers interviewed parents of disabled children throughout Kent who have accessed CAMHS services and found that it has not met their needs.

We would find it helpful if you could discuss this matter with the Chairman of the HOSC and the Chairman of the most appropriate Children and Families Policy Overview and Scrutiny Committee to see whether they could establish a Select Committee, drawn from the two parent committees and the LINk to look at CAMHS.

The Kent LINk Priorities Panel would be happy to discuss how both the LINk and KCC can move forward on this, recognising the scope of this issue.

We attach a copy of the template that was used to bring this issue to the attention of the Kent LINk's Priorities Panel and would welcome your response.

We look forward to hearing from you.

Yours sincerely

John Fletcher
Chairman – Kent LINk Governors' Group

CC'd:

Ian Derbyshire, Senior Commissioning Manager, Kent and Medway NHS and Social Care Partnership Trust

Jenny Brown, Consultant Child & Adolescent in Psychiatry, East Kent Hospitals University NHS Foundation Trust

Merlene Bishop, Head of Children's Support Services, NHS West Kent, Community Child Health Dept, Livingstone Hospital

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Issue for consideration of Priorities Panel

For official use only:

Issue ID Number: ID 047

Date received by Operational Director: 02 / 03 / 2010

Date to Priorities Panel: 10 / 03 / 2010

Office use:

Name:
(JJ, RA, KT, All)

Date completed and initials:

Date of referral to LINk	14 / 01 / 2010 and 27 / 10 / 2010
Date issue arose	As above
Title (headline / short title of issue)	Inadequate provision for young people with Autistic Spectrum Disorder (ASD) from the Child and Adolescent Mental Health Services (CAMHS) and Tier 2 services in Kent

Nature of interest / standing of person in relation to issue *(please 'X' in the relevant column)*

Recipient of service	Family	Friend	Advocate / Campaigner	Other
X				

If other, please state what their standing is in relation to the issue:	

Is the person raising the issue a… *(please 'X' in the relevant column)*

LINk participant	**Member of the public**	**Priorities Panel member**	**Governors' Group member**	**LINk Development Worker**	**Part of an organisation**
X					

If raising an issue on behalf of an organisation, state name and brief details of what they do	The National Autistic Society (NAS) Shepway Branch supports parents of children with Autistic Spectrum Disorder (ASD). They provide crucial ongoing advice, guidance and signpost parents to the necessary services. The organisation plays an essential role to parents whose children have been recently diagnosed with ASD as information provided by statutory services is limited.
Summarise issue (no more than 100 words). If necessary, a more detailed account may be submitted on page 3 with additional pages attached if necessary	This issue was first raised to the Priorities Panel in March 2010. The template provides an update. The NAS Shepway branch has approached the LINk with concerns that an insufficient service is being provided by the Children and Adolescent Mental Health Services (CAHMS) particularly to children with Autistic Spectrum Disorder (ASD). In March 2010, 324 children in Shepway were on the paediatric database having been diagnosed with ASD by the paediatric team. This figure does not include those diagnosed separately by CAMHS staff. Effective help needs to be available for these children. Shepway CAMHS only has three staff not the sixteen they need. The group has reported constant problems with cancellation of appointments due to lack of staff. During further investigation the lack of staff is a problem throughout Kent.

Please use this space to give a detailed account of the issue to be raised with the Priorities Panel *(NB form will expand to accommodate additional text – other documentation can be appended, as necessary)*

1 in 100 children in England have an Autistic Spectrum Disorder, (ASD). Approximately 1 in 10 children who accesses CAMHS has an ASD - not to mention the many that cannot get access. The branch reports that CAHMS is failing to provide an effective service to many children with Autistic Spectrum Disorder at present.

Parents have reported :

- Long waiting lists, for example a year or more for initial assessment.
- No crisis intervention for children with suicidal tendencies or self harming behaviour
- Lack of alternative therapies for example: Cognitive Behaviour Therapy, family therapy, small group, sibling therapy or parenting programmes.
- The service provision for Shepway is different to that which is provided for relatively local areas such as Dover, Canterbury and Ashford. These do not seem to have long waiting lists which are experienced in Shepway.
- Lack of multidisciplinary collaboration between service providers such as speech and language therapists, occupational therapy and paediatricians.
- There is a need for CAMHS staff to be able to offer outreach into schools so they can be involved in observing the children in the classroom setting.
- CAMHS have refused to be involved with pupils who have mental health issues, leaving no other service available to parents.
- CAMHS does not offer any help on an emergency / crisis basis where there is violence by an ASD child to siblings or parents.

This appears to be a national problem, supported by research carried out by the National Autistic Society. 65% of CAMHS reported having supported someone with an ASD, only 10% provided targeted support for this group.

Findings from focus groups children with autism who had received services through CAMHS and their parents by the National Autism Society in summer 2009 echoed the issues raised by the local branch. They also highlighted further issues in their work, as outlined below, showing a wider context of failings with CAMHS services for children with ASD:

- *Lack of autism knowledge and expertise among professionals* – the lack of any specialised knowledge of autism with CAMHS was felt keenly with some CAMHS professionals having little experience of it and many services having no autism specialist staff employed at all. Many interventions, such as cognitive behavioural therapy, need to be adjusted in order to work for children and young people with autism. Without adequate training or access to autism specialists, many professionals remain unable to make such adjustments.

- *Diagnostic overshadowing and the assumption that mental health problems are a 'part' of autism* – professionals often wrongly told parents that anxiety or depression were inevitable consequences of autism, and that they should simply accept this.

- *Misdiagnosis of autism as a mental health problem* – a lack of knowledge of autism within the professional community can present particular problems for young people with autism. Some of the behaviours associated with autism, like sleeping difficulties, personal obsessions, rituals and routines, can easily be interpreted as a mental health disorder to the untrained eye. Misdiagnosis will inevitably lead to inappropriate intervention and existing problems will continue or worsen.

- *Inappropriate or inadequate interventions* – some services offered by CAMHS were not only unhelpful, but had a significant negative effect on their mental health problems. This was often because the professionals involved did not have a good understanding of autism and did not make the necessary adjustments to the interventions offered.

- *A lack of resources* – much needed professionals, for example, occupational therapists (OT) and speech and language therapists (SALT) were felt to be badly needed, yet there was little access to these kinds of professionals. Communication and sensory issues can be a significant factor in increased anxiety, for instance, and OTs and SALTs can be key to addressing these.

- *Family support* – having a child with ASD affected the whole family, yet there is little support available for parents and siblings within CAMHS with most either unsupported or relying on charities and other local organisations.

- *Parents blamed for child's problems* – parents themselves were often blamed by professionals for their child's mental health problems or autism because of a lack of parental love, bad parenting skills, or being over-anxious or over-protective.

- *Non-existent transition planning* – further problems with teenagers were apparent as the transition from CAMHS to adult mental services brought extra difficulties, as nothing was in place that supported them at this crucial time.

The need for support and early intervention for children and parents is addressed in the Department of Health's New Horizons: Towards a Vision of Mental Health strategy which was launched recently following consultation.

Is the issue currently under investigation via a complaint or inquiry, being dealt with by somebody else? *This includes being part of a wider campaign on the issue*	**Yes**	**No**
	X	

If yes please give details of actions already taken including contact details of others dealing with the issue

The National Autistic Society has launched a national 'You Need To Know' campaign, (copy attached), to improve support for children with autism who also have a mental health condition. Their research so far has looked at the support which is provided by CAMHS services for this group and identified areas for improvement as stated above. They support this request for the LINk to carry out a review by the local branch and are looking for LINks across the country to review services in each area in order to give a local focus to the campaign.

Contact: Sarah Best (Campaigns Officer – Local) at the National Autistic Society.

Research has also been completed by Canterbury Christchurch as part of the CAMHS Pathway Project. This gives examples of interviews with parents of disabled children throughout Kent who have accessed the CAMHS service and found that it has not met their needs. (Copy of report attached)

In addition to this, on 29 September 2010 LINk held a workshop to invite parents, carers and staff to discuss their experience of CAMHs. Louise Chapman Associate Director of Children's and Adolescent Mental Health Service Kent and Medway NHS and Social Partnership Trust presented figures which highlight the referrals in West Kent: Canada House 1052 (consistently one third Swale and two thirds Medway), Gatland House Maidstone 748, Twisleton Court DGS 729, Homeopathic Hospital SW Kent 612, Total 3141 referrals into Tier 3/April 2009/10 Details were also provided which demonstrated the differences between the National Service Framework recommendations for staffing of the service and the actually. (Copy of presentation attached)

The key message from that workshop was the lack of Tier 2 provision for young people (which is family and therapeutic support). This has resulted in cases being scaled into Tier 3, which represents crisis intervention. Therefore failing young people and their families.

The Kent LINk has also been approached by the Woking LINk to discuss this issue. They have participants who also have concerns about the CAMHs service in their area. This may indicate a problem with CAMHs nationally and not only in Kent.

Is there a timescale / deadline / circumstance affecting this issue that may mean the LINk will have to act quickly? *Eg closure of a unit, change of service, a particular urgency*	**Yes**	**No**
	X	

If yes what are the circumstances and what is the timescale by which action has to be taken?

Any actions to be completed by 31 March 2011, due to LINk's funding ending.

What expectation does the person raising the issue have of the LINk? *Ie what does that person want the LINk to do / what action to take*

The CAMHs service in Kent is commissioned by all three PCT's in the county. The service is provided by multiple agencies. For example: Kent and Medway NHS and Social Care Partnership Trust, Voluntary organisations, Maudsley, East Kent Hospitals Trust Community Services, Family Action, Action for Children and the N.S.P.C.C.

1. Investigate consistency of CAMHS services throughout Kent, highlighting any inequalities of service. Ask the lead commissioner to provide:
    a) A map of where CAMHs are provided in Kent
    b) The name of the provider organisation
    c) Details of which services are provided from that site.
    d) Waiting times to services
    e) Staffing ration in line with National Service Framework recommendations

2. Approach the lead commissioner of CAMHS to find out:
    a) The reasons for the staffing shortages in West Kent and other districts and what positive measures they are taking to improve the situation and when will they be implemented.
    b) What other services can CAMHs implement locally to help parents and siblings of ASD children, i.e. siblings support groups, parent information groups, additional support workers to help children, who are unable to leave the house with their parents, to gain independence and personal development to overcome social anxiety etc.
    c) Working at Tiers 1 and 2, how they could offer more support at school to work

with a child, educate school staff about the disability and how best they can collectively help the child. Offer effective outreach programmes from CAMHs to other professionals about ASD.

What would be a good outcome from the perspective of the person raising the issue?

- For a significant improvement to resources to support CAMHS teams throughout Kent to support children with ASD. In particular, at least, an equal service in Shepway, to that in other CAMS services in Kent.
- A transparent pathway to the services of CAMHs including access to Tier 2 services
- An effective early intervention, Tier 1 and 2 service to increase well being of children with mental health issues and their families, enrich the child's opportunities as well as their future life skills and experiences and allow them to develop independence. Depending on where the child was on the spectrum, this would limit the need for extensive adult services when appropriate early therapy has taken place.
- Effective outreach programmes from CAMHS to other professionals about young people's mental health issues, to encourage a joined up approach to benefit the child.
- Availability of alternative therapies as an alternative to drug therapy, which appears to be usually the first port of call.

What evidence does the person raising the issue have to support the case they are putting for the LINk to take action? *List or attach evidence and sources, if available*

Personal statements from parents affected by this issue – evidence attached. Evidence from Canterbury Christchurch University project. Research from National Autistic Society

How widely does this issue affect other people?

In 2004, the Office of National Statistics (ONS) reported that 30% of children with autism had another clinically recognisable mental disorder, as compared to 10% of all children and young people.

In a more recent study of children with autism between the ages of 12-14, researchers found that 70% of participants had at least one co-morbid mental disorder, while 41% had two or more, such as social anxiety disorder, attention deficit and hyperactivity disorder, oppositional defiant disorder and depression.

Failure to get adequate support affects everyone who is involved with the child; this includes schools, relatives, families and the child's peers. The lack of professional support can cause severe depression for the child and family alike which has resulted in the break up of families, and ill health of carers. Siblings suffer from depression and ultimately do not want the disabled child to be part of the family. This tension creates further anxiety and stress for parents and leads to the inability for families to have outings or socialise thus causing a sense of isolation for the child and family.

In what ways are other people affected by this issue?

- Lack of support and understanding for the disorder causes family members to experience low self esteem and results in the inability to cope. Issues at school and refusal to attend school.
- Teachers not knowing how to cope and handle the child can lead to the child being excluded.
- Lack of respite intervention reduces the chance for parents to partake in activities outside the home

Name / Signed	Date
Cate Boland	1 November 2010

Responses from parents about their experience of CAMHS

First submitted in January 2010

“My son has been referred to CAHMS via speech therapy to assess for ADHD. That was over a year and half ago and I had a letter back saying there is a long wait and nothing since. I don't know what’s going on, whether they have decided not to assess him after all or he is still waiting. Who knows?”

“My daughter is no longer in school due to her extreme anxiety; it just got too difficult to get her there. The school have applied for a statement (again!) and we are waiting for a referral to hospital schools. Anyway the reason I am telling you all this is because we were referred to CAMHS twelve weeks ago for her anxiety. We had the first assessment appointment last Thursday; we were warned there was a waiting list. They diagnosed her as having extreme anxiety causing her to be school phobic. This all goes with her diagnosis of ASD and selective mutism. We were not told of any support groups. We are now on a waiting list for her to have some art and play therapy. We did not know about the out of hours service”.

“My experience was very negative....I was having the worst time imaginable with my son and they said that the Dover CAHMS do not accept children with ASD...even though other areas do! My son’s paediatrician even wrote to them and said they should be involved and they still would not help!”

“At the time of referral to CAMHS by the paediatrician, my son’s behaviour was spiralling out of control. Despite really risky situations we had to wait for months for an initial appointment. I believe that there are long and long waiting lists and that referral is determined by crises (rather than preventing them!). You get seen when things get dicey! However, I have to say once you are in the system you tend to be ok. Of course this depends on the quality of who you see”.

“We have been visiting CAMHS in Shepway since last August-ish when we moved from London. We used them in London for about two years and used the service as kind-of a brainstorming for strategies for management of our son's behaviour and problem areas. With the Shepway CAHMS, we didn't have to wait very long, however, when we have seen them, the person hasn't really been very helpful. He has asked how our son is doing, and we tell him the positives and the areas we have problems with. He asks what medication he is on and if we need any prescriptions, he makes notes on what we say then he says he'll see us again in six months. We haven't been given any information regarding our child's conditions at this stage of his life. We've been given no details of further support - especially having moved to the area from London 18 months ago, it would have been handy. We haven't been offered any therapy services, and actually, our son has an ASD and epilepsy and speech and language disorder and ADHD. We have had no therapy or support offered for his siblings or the family. We were never aware of out of hours services. I actually don't understand what the point of going to CAHMS is and what the benefit is. The person there is not very understanding towards my son's issues and the effect it has on us. Despite my feelings towards CAHMS, I continue to go with my son because I feel that if we refuse any service offered, then if you need it again its back to the waiting list, and in London we found it so helpful.”

"We originally started on CAMHS Tier 2, until our son became very depressed etc and after an assessment with a psychologist we were escalated quickly to the services at Tier 3. We attended whilst in Tier 2 meetings as a couple to talk over our feelings and perhaps strategies of dealing with our son's behaviour etc. They were supportive but short staffed. We have been seeing monthly until recently the Consultant and a Family Psychotherapist as a whole family. The Consultant is usually able to come back to us quite quickly if we have encountered any major problems. Our visits are now termly especially as our son is now at specialist school all week".

"Our daughter is now almost 16 and has had absolutely no support in any way whatsoever. She eventually had a CAHMS assessment a year ago after a 13 month wait. She currently has just begun 4 hrs a week home tuition following some school bullying last September since when she has not been back to school".

Responses from parents about their experience of CAMHS

Submitted to LINk Priorities Panel November 2010
Email 28 April 2010 - Complaint from parent to CAMHs:

The email below has been sent by a parent. The teenager has a diagnosis of ASD and SM (Selective Mutism) and has had appointments cancelled on and off in the last four years by professionals at CAMHS, Cherrytree, who either went on long term sick leave or left the service. Parents then got in contact with SALT who offered help and therapy for a year and were making progress, then referred back to CAMHs. Having waiting four months for their appointment you can see what happened below.

"Dear T
We have received your letter and I am astounded at your interpretation of events. I am tired of talking to CAMHs and not being listened to and so is MI.

You had two sessions with M and decided to cancel the third because you where as we were told (rightly or wrongly) by your secretary at a conference.

M then said that there was no point then in going as you were not interested. You left an odd message about wanting a meeting with a couple of days notice with the manager and M which was unreasonable as we did not know why. We then discussed this on the phone but by that time M had already made up his mind that you didn't want to help him at all. He has clear perception of people and their intentions.

It became also clear that you had no idea of SM when you asked him to stay without me in the first session however he agreed and stayed in with you for an hour.

He came out saying that you talked but he didn't understand how that would help him as he knows what CBT was. I came back in to inform you of this straight away. He is highly intelligent and can read up on this!

He did not and does not want to go back in time discussing what might have caused anxieties in his life before but wanted help with moving on and preparing him for what was ahead, i.e. College.

This we pointed out at the meeting we had previously and we also pointed out that this would be achieved with the program SALT wrote. He had asked me to stay with him for the second session which you were surprised about but then agreed to.

We asked you if you had read the SM Program for Teenagers MJ wrote and your answer was 'no'. How then can you know what we were talking about? As a professional would you not want to read about what a child's therapy had been before and how it was successfully implemented so that future therapy could be worked the same?

He realised that you had no interest in following the program up and in knowing what he had achieved so far by following it.

You were talking about a six week assessment period but could not explain what sort of assessment it was you were doing. M needed to know, we asked and what you showed him was not relevant to him as he could not talk to you nor writes down in front of you what he thought. This we explained but did you understand this? He had to build up trust with you first and this was not happening because he did not know what you wanted to do and were expecting him to be in the room by himself with you.

It is questionable why staff were trained and had SALT's program at Cherrytree if it is not being used - and a complete waste of resources and money.

We always said that we wanted continuation of what (SALT) had been doing but needed additional help and M had always offered her help to any professional working with M as she herself could not. This is what M wanted but now has lost all and complete trust in Cherrytree and does not ever want to go back there.

For you to interpret it the way you have has shown me that you just wanted to stay within your own safety net and tick boxes of what you have done rather then inform yourself about what M had already done and should have continued.

I would hope that you re-evaluate your own professional status and refocus on the child's needs rather then on 'what the service can provide' attitude. I can see that it has been easy to close M's file and maybe that was the aim, another box ticked.

We just hope that M will be ok in September as we can now not see anywhere else he can go for help if he isn't.

My question also is how many other children/parents have to go through this and why parents and children are not being listened to when they clearly state what they are hoping to achieve".

Email 26 September 2010

"Hi Cate
I have been visiting Nicola getting and providing info for about a year now. I live in Whitstable and came across her after some one told me about the Faversham Rottweilers LOL it took me

a long time to find any one with support. My story is similar to that of H, I have my own support group which consists of friends and a few acquaintances with similar problems of accessing services through CAHMs among other services. I myself have had countless meetings with no outcomes and am currently on a waiting list for Guys Hospital to find out answers and help.

I am sorry for short notice but would like to represent these people on the treatment they receive from CAHMs One main issue is lack of follow through and the fact that they talk to the parents about issues that parents feel the kids do not need to know. Parents and children leave feeling more upset and traumatised by the whole event (me included) Assessments are concluded from this. I have had one friend's child who recently ended up in hospital with a broken cheekbone among other things due to her lack of knowledge and understanding of his situation.

It scares me that these parents and children are left to there own devices, with no help or understanding. I am concerned for my child's safety and others I would like to put this across. Even for the children that do not fit their criteria they or there parents may still need the right help. I am tired of chasing services to find a black hole at the end, I have had Team around the child meetings social service involvement and exclusions from school, I am lucky he is in a good school now, but problems still exist. CAMH's working with the LEA and schools is crucial and yet every one seems to pass the buck.

If I can help please do not hesitate to call".

Official complaint 5 October 2010

"Our son was referred to your service over a year ago. We have made many telephone calls within this time to find out how much longer he had to wait to be seen, only to be told each time that someone would call us back - which they never did, not once.

On Friday, 2 July 2010, K tried to hurt himself many times, in many different ways. He even tried to run out in front of a fast moving tractor as it was just about to pass him. If it wasn't for my fast reactions grabbing his fleece and dragging him out of the way and back onto the pavement, he would have gone under the front wheel – which was a lot bigger than him self and would have probably killed him. I telephoned Canada House to get some help, only to be told to call back Monday as no one was available....Obviously I refused. I said I needed to speak to someone urgently and immediately and explained that my son had tried to kill himself a number of times that morning. It was only then the receptionist put me through to someone, who took some details. This lady said that the on-call Doctor was out on a call and she would get them to ring us when they returned.

Dr Vanstraelen returned our call when he got the message, and after we explained what had happened that morning, asked us to bring K in to see him that afternoon, where they had a chat and a review appointment made for two weeks after. In the meantime a detailed report about K was sent to Dr Vanstraelen from Dr Kate le Maréchal, Lead Clinical Psychologist with the Guy's Cleft Services. A copy of which is appendix 1".

Email 16 October 2010

I sent a copy of my latest guns a blazing letters addressed to our MP in support of the 'You Need to Know' campaign to Margret Pau (NAS Shepway) who in turn sent me an email about her meeting with you. I am one of those frustrated emailers that she presented to you.

I have spent the last nine months having an intense fight with KCC and their education department (with a previous 2 years with the school) and also the DLA. However CAHMS seem unbeatable - our GP, MP and my wife and I cannot get any further action other than someone will come back or there is nothing they can do. Our son is aged 9, so cannot be seen by Dr Gulam for his ASD / ADHD.

Under 8s, I understand have excellent services, but all I am aware of are ISIS and the bloody CAHMS (that is me being polite).

Our Doctor referred our son to CAHMS in July - last year. As there was no alternative made available, we resorted to going private for an assessment. Our doctor referred us to the Priory and within the month Dr Blemcow gave us an excellent assessment report, he also initiated a drug programme for our GP to prescribe.

With an effective statement, new school and a calming drug, we are very, very happy - for now. I am very intrigued to know what these other options are available to the GP; maybe you would enlighten me with them.

Sorry I am not convinced that with changes planned for April 2011, suddenly the huge backlog that CAHMS have will disappear and every one will get the treatment they are entitled to - I have heard it all before!

Despite my negativity I always believe that someone is there somewhere who will help find the light at the end of the tunnel, if I can be of help, so I would be be interested to be involved as a parent of two children with ASD".

End.