

003208/15

REGISTERED NUMBER: 05469735 (England and Wales)

ABBREVIATED UNAUDITED ACCOUNTS FOR THE YEAR ENDED 30 JUNE 2013

FOR

DECIPHA CIC

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A04 28/03/2014 #219

COMPANIES HOUSE

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A14 20/03/2014 #255

COMPANIES HOUSE

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DECIPHA CIC
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FOR THE YEAR ENDED 30 JUNE 2013

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DECIPHA CIC
COMPANY INFORMATION
FOR THE YEAR ENDED 30 JUNE 2013

DIRECTORS:

Ms J Hoskins
N J Catlin
Ms C Barry
Ms A Gill

SECRETARY:

N J Catlin

REGISTERED OFFICE:

CAN Mezanine
49-51 East Road
London
N1 6AH

REGISTERED NUMBER:

05469735 (England and Wales)

ACCOUNTANTS:

Pearson McKinsey
55 Beulah Road
Walthamstow
London
E17 9LG

DECIPHA CIC (REGISTERED NUMBER: 05469735)

ABBREVIATED BALANCE SHEET
30 JUNE 2013

	Notes	30 6 13 £	30 6 12 £
CURRENT ASSETS			
Cash at bank		4,891	5,599
CREDITORS			
Amounts falling due within one year		9,152	10,825
NET CURRENT LIABILITIES		<u>(4,261)</u>	<u>(5,226)</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>(4,261)</u>	<u>(5,226)</u>
CAPITAL AND RESERVES			
Called up share capital	2	100	100
Profit and loss account		<u>(4,361)</u>	<u>(5,326)</u>
SHAREHOLDERS' FUNDS		<u>(4,261)</u>	<u>(5,226)</u>

The company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 June 2013

The members have not required the company to obtain an audit of its financial statements for the year ended 30 June 2013 in accordance with Section 476 of the Companies Act 2006

The directors acknowledge their responsibilities for

- ensuring that the company keeps accounting records which comply with Sections 386 and 387 of the Companies Act 2006 and
- preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of each financial year and of its profit or loss for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company

The abbreviated accounts have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies

The financial statements were approved by the Board of Directors on behalf by

28/2/14

and were signed on its



N J Catlin - Director

The notes form part of these abbreviated accounts

DECIPHA CIC

**NOTES TO THE ABBREVIATED ACCOUNTS
FOR THE YEAR ENDED 30 JUNE 2013**

1 ACCOUNTING POLICIES

ACCOUNTING CONVENTION

The financial statements have been prepared under the historical cost convention and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008)

TURNOVER

Turnover represents net invoiced sales of goods, excluding value added tax

2 CALLED UP SHARE CAPITAL

Allotted, issued and fully paid

Number	Class	Nominal value	30 6 13 £	30 6 12 £
100	Ordinary	£1	<u>100</u>	<u>100</u>

ATM

CIC 34**Community Interest Company Report**

For official use
(Please leave blank)

Please
complete in
typescript, or
in bold black
capitals.

Company Name in
full

Decipha CIC

Company Number

5469735

Year Ending

2013-30-6

This template illustrates what the Regulator of Community Interest Companies considers to be best practice for completing a simplified community interest company report. All such reports must be delivered in accordance with section 34 of the Companies (Audit, Investigations and Community Enterprise) Act 2004 and contain the information required by Part 7 of the Community Interest Company Regulations 2005. For further guidance see chapter 8 of the Regulator's guidance notes and the alternate example provided for a more complex company with more detailed notes.

PART 1 - GENERAL DESCRIPTION OF THE COMPANY'S ACTIVITIES AND IMPACT

In the space provided below, please insert a general account of the company's activities in the financial year to which the report relates, including a fair and accurate description of how they have benefited the community, or section of the community, which the company is intended to serve.

See Decipha CIC Impact Report and Accounts 2013 attached

(If applicable, please just state "A social audit report covering these points is attached").

(Please continue on separate continuation sheet if necessary)

PART 2 – CONSULTATION WITH STAKEHOLDERS – Please indicate who the company's stakeholders are, how the stakeholders have been consulted and what action, if any, has the company taken in response to feedback from its consultations? If there has been no consultation, this should be made clear

See Decipha CIC Impact Report and Accounts 2013 attached p18

(If applicable, please just state "A social audit report covering these points is attached")

PART 3 – DIRECTORS' REMUNERATION – if you have provided full details in your accounts you need not reproduce it here Please clearly identify the information within the accounts and confirm that, "There were no other transactions or arrangements in connection with the remuneration of directors, or compensation for director's loss of office, which require to be disclosed" (See example with full notes) If no remuneration was received you must state that "no remuneration was received" below

See Decipha CIC Impact Report and Accounts 2013 attached

PART 4 – TRANSFERS OF ASSETS OTHER THAN FOR FULL CONSIDERATION – Please insert full details of any transfers of assets other than for full consideration e.g. Donations to outside bodies. If this does not apply you must state that "no transfer of assets other than for full consideration has been made" below

None

(Please continue on separate continuation sheet if necessary)

(N.B. Please enclose a cheque for £15 payable to Companies House)

PART 5 – SIGNATORY

The original report must be signed by a director or secretary of the company

Signed

Nick Col

Date

18/3/14

Office held (tick as appropriate) ☒ Director ☐ Secretary

You do not have to give any contact information in the box opposite but if you do, it will help the Registrar of Companies to contact you if there is a query on the form. The contact information that you give will be visible to searchers of the public record

nick@decypha.org.	
Telephone	
DX Number	DX Exchange

When you have completed and signed the form, please send it to the Registrar of Companies at:

For companies registered in England and Wales: Companies House, Crown Way, Cardiff, CF14 3UZ
DX 33050 Cardiff

For companies registered in Scotland: Companies House, 4th Floor, Edinburgh Quay 2, 139
Fountainbridge, Edinburgh, EH3 9FF DX 235 Edinburgh or LP – 4 Edinburgh 2

For companies registered in Northern Ireland: Companies House, 2nd Floor, The Linenhall, 32-38
Linenhall Street, Belfast, BT2 8BG



2013

Decipha CIC Impact Report and Accounts

RoadMap for life

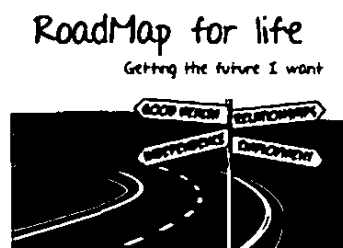
Getting the future I want



Nick Catlin, Dr Janet Hoskin, Celine Barry

Decipha CIC

13/3/2013

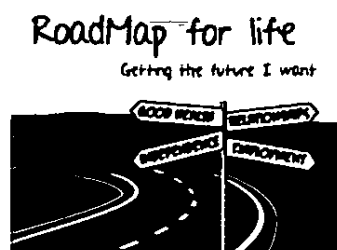


Decipha CIC Impact Report and Accounts June 2013

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1. Community Interest Statement

We are a non profit Community Interest Company (05469735) regulated by the Department for Business Innovation and Skills. Decipha CIC has been set up to benefit young people and adults with neurological conditions who have special and additional needs. We give advice and support to their carers and family members. Decipha CIC reinvests any profits above working costs and salaries to support programmes for young people in the community.

We aim to ensure that young people with complex education and medical special needs, their families and carers will be better supported in the future. We will provide training and coaching to enable every young person and adult with complex needs to have a person centred plan that fully meets the aspirations of the family.

Through individual specialist learning, behaviour and IT assessments we will offer interventions that will improve young people's literacy, maths and communication skills. We will provide resources, training and access to information that will support young people and their families through life changing transitions from childhood to adulthood.

2. Evidence of Need in Numbers

Inequality in Health Outcomes

40,000 the number of children with life-limiting conditions in the UK under 19 years due to advances in long term medical management - University of Leeds 2012¹

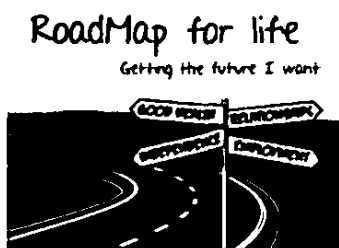
1180 young people living with life threatening medical conditions in the West Midlands alone - The Big Study published by Together for Shorter Lives in 2012²

1000 families were meeting family care costs of £8.7m a year in the West Midlands region. Annual hospital care estimated as £8.4m and non hospital care at £1.3m. The cost of short breaks at £3.7m -- The Big Study published by Together for Shorter Lives in 2012.

80% of mothers who care for a young person with Duchenne Muscular Dystrophy reported clinical levels of anxiety or depression (Muscular Dystrophy Campaign research into 'Becoming

¹ L Fraser et al Rising National Prevalence of Life-Limiting Conditions in Children in England, Pediatrics 2012,129 1-7

² www.togetherforshorterlives.org.uk/assets/0000/4435/TfSL_The_Big_Study_Final_Research_Report_WEB.pdf



an adult, -Transition for young men with Duchenne Muscular Dystrophy (Abbott and Carpenter 2010)³

45% of adult men living with Duchenne Muscular Dystrophy are cared for exclusively 24/7 by parents or a family member (n=69) - DMD Pathfinders Survey 2013⁴

46% of adults living with Duchenne Muscular Dystrophy spent only 1-2 days per week outside of their home – DMD Pathfinders Survey 2013

83% of adult men living with Duchenne Muscular Dystrophy are single (n=94) - DMD Pathfinders Survey 2013

80% of adult men living with Duchenne Muscular Dystrophy are not in work (n=94) - DMD Pathfinders Survey 2013

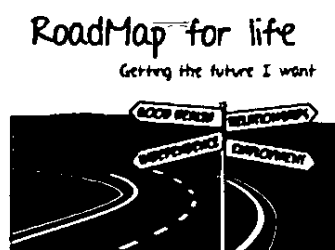
During a three year period to 2012 the Charity Action Duchenne and members of the Decipha Team consulted over 100 boys and young men aged 13-25 living with Duchenne Muscular Dystrophy in the UK to evaluate techniques and barriers to engagement with the organisation. Evaluation techniques used during this period include, questionnaires, vox pops, use of arts based projects, internet forums, skype calls, and workshops.

Key findings include

- a) Participants were unable to plan and commit to small projects. They did not possess the ability to take charge and control and action change requiring continued intense support and regular daily contact from the Charity resulting in an over reliance on one member of staff.
- b) Parents were busy with working and often didn't have the time to support their young person to be fully involved in projects.
- c) Boys and young men have reported difficulties developing and sustaining sexual relationships.
- d) Use of new media techniques at the beginning of projects (forums, regular skype calls, regulated use of social networking between boys and young men and females on the project via the charity website) worked at ensuring some level of commitment and routine which, over a number of months can then be turned into actual commitment to attend workshops.
- e) Core triggers of depression in older boys were isolation and rejection within relationships, both sexual and platonic.
- f) Overly fearful of travelling to new places and not feeling in control or fully understanding their health condition.

³ Abbott, D & Carpenter, J (2010) Becoming an Adult Transition for young men with Duchenne Muscular Dystrophy (DMD), London Muscular Dystrophy Campaign

⁴ DMD Pathfinders Facebook group



Social Deprivation

You are much more likely to have a free school meal if you have a Special Educational Need (SEN) and also if you have a statement for behaviour, emotional and social difficulties (Children with SEN 2010 An Analysis DfE)⁵

20% attainment gap for gaining level 4 or above in English and Maths for those on Free School Meals (57.9%) compared to all other pupils (77.9%) in 2011 - Department of Education (2013)

27% attainment gap for achieving A*-C GCSE English and Maths 2011 for those pupils on Free School meals (35.1%) compared to all other pupils (62.5%) - Department of Education (2013)

34.6% of students who have free school meals get 5 or more A*-C GCSE's including English and Maths compared to 62% non free school meals (NPC outcomes and learning 2013)⁶

Inequality in Educational outcome

21% of all school pupils in 2010 had SEN (Children with SEN 2010 An Analysis DfE)

95% of primary Special Educational Need is not defined as a severe or profound learning difficulty

157,960 young people in England assessed as having Emotional, Behavioural and Social problems (DfE 2010)

78,135 pupils have identified SEN as a specific learning difficulty (dyslexia or dyspraxia) 2011 (Parliamentary Question 26th April 2012)⁷

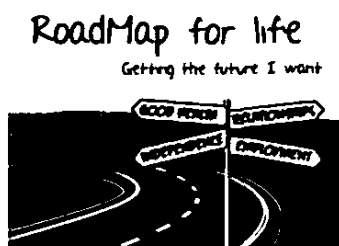
10% population diagnosed with dyslexia of which 4% is severe (British Dyslexia Association website 2013)⁸

⁵ <https://www.gov.uk/government/publications/children-with-special-educational-needs-2010-an-analysis>

⁶ <https://www.thinknpc.org/publications/outcomes-map-education/>

⁷ <http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120426/debtext/120426-0001.htm>

⁸ <http://www.bdadyslexia.org.uk/about-us.html>



47.4% attainment gap between those assessed for SEN (22.1%) compared to those with no SEN (69.5%) for 5 or more A*-C GCSE's including English and Maths (NPC outcomes and learning 2013)

220,000 16-24 year olds NEETS (Not in Education, Employment or Training) with a disability in England 2011 (Parliamentary Question 25th Jan 2012)⁹

Attention Deficit and Hyperactivity Disorder (ADHD) is a common disorder. In the UK, surveys of children between the ages of 5 and 15 years found that 3.62% of boys (approx 200,000 - on average 8 boys per school in the UK) and 0.85% of girls (approx 46,000) had ADHD (AADD-UK 2013)¹⁰

Social Exclusion

9 times more likely to be permanently excluded from school if you have a SEN (NPC outcomes and learning 2013)

50% of the prison population has been diagnosed with dyslexia (from severe to borderline measures) (Kirk and Reid 2001)¹¹

80% of all adult prisoners are at or below the level expected of an 11 year old in writing, 66% in numeracy and 50% in reading (Dyslexia in the prison service report)¹²

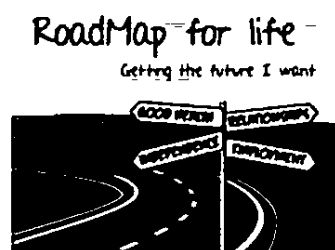
Undiagnosed ADHD in adults may have severe consequences including academic failure, substance abuse, criminal activity, failed relationships, troubled work relationships, and emotional difficulties such as anxiety and depression (AADD-UK 2013)

⁹ <http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120125/text/120125w0001.htm>

¹⁰ <http://aadduk.org/symptoms-diagnosis-treatment/>

¹¹ Kirk, J & Reid, G (2001) An examination of the relationship between dyslexia and offending in young people and the implications for the training system. *Dyslexia* 7(2), 77-84

¹² <http://dyslexia.levon.info/>



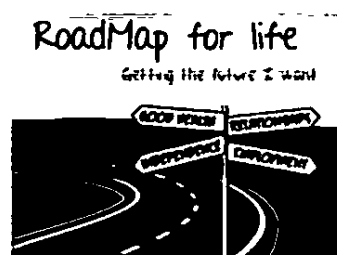
3. Mapping Decipha Outcomes

Table 1 Mapping Decipha Outcomes and Impact

Unmet Need and Lagging Skills in our Community	Activities	Solutions	Outcomes	Impacts
Social and emotional aspects of living with a neuro-developmental disorder.	Assessment and identification of young person's lagging social and emotional aspects of learning Solution Focussed approach to developing new skills through preferred futures Might include inflexibility, change of mindset, persisting on tasks, handling uncertainty, empathising with others, impulsivity, starting conversations, black and white thinking, poor planning and organisation	Solution focussed sessions with Decipha Solutions, 360 degree school, home sessions, planned interventions 5 x 1 hour sessions and a 360 Review	Improved meta-cognition evidenced through development of self reflection, self esteem, communication, asking questions, starting and sustaining friendships, greater flexibility in thinking, planning and organisation A Person Centred Plan that identifies the individual's aspirations and needs	Improved GCSE results Improved punctuality and attendance at school Improved APS for pupil and cohorts across National Curriculum subjects
Reading	Assessment of young person's reading age and skills, Synthetic phonic programs, Decipha Reading and Literacy online Language development programmes	Each pupil is assessed, full report, 4 x week 20min sessions	Reading Age score improved by 1 year	Decrease in incidents that could lead to exclusion from school Improved ability to become an active citizen in school and the community, less isolation and ongoing mental health problems
Spelling	Assessment of young person's spelling age and skills, synthetic phonic programme, Decipha online Reading and literacy	Each pupil is assessed, full report, 4 x week 20min sessions	Spelling Age score improved by 1 year	



Writing and Organisation of information	Assessment and analysis of young person's writing skills and viewpoints, Assessment of comprehension skills, Decipha online literacy programme	Each pupil is assessed, full report, 4 x week 20min sessions	Writing skills improved, ability to express viewpoint and organise research and information	Evidence of improved personalisation to meet pupil and adults needs
Language delay and disorder	Referral of young person to partner SLT	Weekly individual programme	Expressive and receptive language improved	
Number	Assessment of young person's number and mathematical skills, assessment for dyscalculia, Intervention using Dynamo Maths and other bespoke programmes	Student assessment, full report, number and maths intervention	Number and maths skills improved by 2 National curriculum sub levels	
Training, CPD and awareness raising for Education, Health and Social Service professionals of the complex SEND for young people and adults living with neurological conditions and rare diseases	Workshops and Conferences	Professional development sessions Online blogs on key issues Use of social media to disseminate best practice. Tool Kits	Better understanding of the complex needs of young people adults and their families living with rare diseases Improvement in the targeting and management of interventions Improved collaboration between agencies in meeting needs	Improved destination outcomes beyond school such as college apprenticeships, supported internships, employment and other training opportunities
Development of a holistic life plan from 0-25years	Person centred Planning meetings to raise awareness and expectations about aspirations and developing new skills	RoadMap for Life Programme	Well co-ordinated planning for the future for young adults	Better personal control over medical diagnosis and support

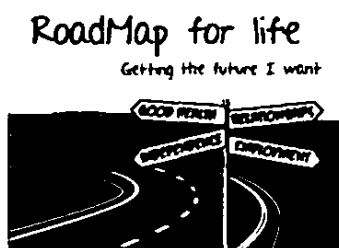


<p>Role Models and Leadership from adults living with complex medical conditions and rare diseases</p>	<p>Involvement in project steering committees Developing user led resources</p>	<p>Developing young people's skills and enabling them to celebrate their own personal successes in life</p>	<p>Identifying and supporting a new layer of leadership in the Community</p>	<p>Better housing and opportunities for independent living</p> <p>Young people more able to make friends and take part in community events A wider circle of support</p>
<p>Why is this important?</p> <p>It is important to identify any lagging skills following the identification of a SEN. Having emotional and behaviour difficulties for example labels the problem but does not identify the skills that the young person needs to address.</p> <p>A young person and their family need a plan for life.</p> <p>Rare medical conditions can be complex and supporting young people will often require multi agency advice and resources</p>	<p>Why is this important?</p> <p>Decipha focuses on assessment, programmes and interventions that can help to directly improve identified skills ¹³ Opportunities for ongoing CPD is essential</p>	<p>Why is this important?</p> <p>Decipha recognises the need to provide planned interventions that are frequent, short and intensive This model requires school staff and home training that also allows for wider use in the community ¹⁴</p> <p>Professionals need to be able to offer meaningful advice and guidance based upon a clear understanding of the aspirations of the young person</p>	<p>Why is this important?</p> <p>Specific and measurable improvement in skills for individual young people ¹⁵ Planning is well coordinated between professionals on the ground and delivered according to the needs and aspirations of the young people and their families</p>	

¹³ Research published by Dr Ross Greene for his Collaborative Learning methods and assessment of lagging skills www.livesinthebalance.org and Brief Therapy Training www.brief.org.uk

¹⁴ "Seeing beyond the Wheelchair Learning and Behaviour issues and intervention in Duchenne Muscular Dystrophy" J A Hoskin PhD Thesis pub Swansea University 2011

¹⁵ "Seeing beyond the Wheelchair Learning and Behaviour issues and intervention in DMD" J A Hoskin PhD Thesis pub Swansea University 2011



4. What We Do

Supporting young people with a complex medical need and their families to take control of their education, health and care

A Roadmap for Life - for chronic and palliative conditions

Due to the changes in life expectation for young people with a chronic medical condition there is an increasing need to review the way that health and education, employment and housing is assessed and provided for those with a long term life limiting condition like Muscular Dystrophy. The University of Leeds research would suggest that 40,000 young people are currently expected to live longer and into adulthood due to better medical care and interventions.

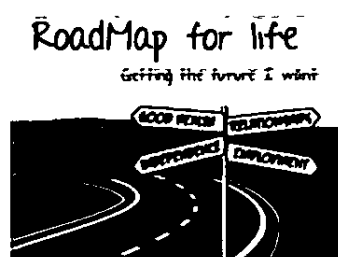
Decipha is aiming to develop a toolkit of resources that will enable young people and their families living with chronic and life limiting conditions across the UK to identify key milestones in planning for life and gaining access to current provision.

For all families the journey of having a child diagnosed with a life limiting condition is fraught and difficult to navigate and few have any experience of how to access information and resources so they can do the best for their children. It is, for example, very important to understand that expert medical treatment for young people with conditions like muscular dystrophy, cystic fibrosis, spinal muscular atrophy and cerebral palsy can now offer a significant improvement in length and quality of life. All members of the Decipha Team have personal and professional experience of supporting families through this journey by giving information, advice and guidance.

We are building resources to offer individual coaching sessions, e learning training and workshops that will focus on emotional support, genetic diagnosis, best medical interventions, new genetic drugs and therapies, independent living, housing, multi agency support, managing personal budgets, educational assessment, further education and training opportunities.

This toolkit of resources and training should provide the backdrop to a person centred plan for the young person that every family will develop to create their own personal roadmap.

We implement solutions rather than dwelling upon problems and ensure user led ownership of the project and outcomes.



Through a solution focused and person centred approach young people will be encouraged to plan personal pathways for developing relationships, healthcare, housing, education, training and employment. This will include opportunities to be able to discuss the complex emotional and social issues surrounding living with life limiting conditions. The plan will also include recording important accident and emergency information and key contacts involved in the expert medical management of this user group. It can easily be shared at key milestone meetings such as Education, Health and Care plan reviews including those specific to Transition and those specific to specialist Medical Centres of Excellence.

We will offer the young person a roadmap for navigating complex decisions into adulthood that will include improved control over managing their medical condition, access to personal care provision and managing personal budgets. Planning needs to start early in terms of identifying education and training qualifications that can lead to employment. We aim to offer parents and young people options for independent living.

We will provide direct support for families from diagnosis and training opportunities for education and health professionals. We would aim to offer this nationally through social media, a website and regional workshops and Conferences.

Neuro-developmental disorders with associated lagging emotional, communication and social skills - Working with conditions such as ADHD, Dyslexia, Dyspraxia, OCD, Aspergers, ASD

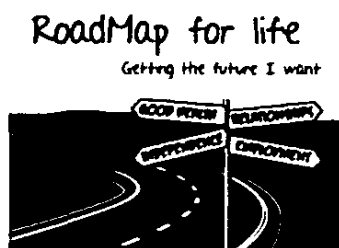
Meeting Special Learning Needs

1 in 5 children are identified in need of Special Educational support or extra teaching. In some schools this will be much higher. This can represent 6 or more children in any classroom.

Decipha also recognises that some children experience neuro-developmental delay in acquiring key skills that can have a significant impact on their learning and behaviour. These can be learning to read, spell and write. They can also be described as lagging cognitive skills that affect emotional, communication and social behaviour.

Decipha offers assessments for reading, spelling, literacy working memory and dyslexia. We can assess for Dyscalculia and problems with numeracy and Maths.

Specific and clear feedback is built into our Decipha reading programme. We see this as a cost effective and positive way to improve a learner's performance. Feedback in our Reading programme includes parental or school teacher or LSA immediate feedback during sessions and



through our blogs. The programme has modular assessments to review and feedback on progress made every 3 weeks.

Young people with SEN are commonly at risk of having poor meta cognitive skills that are key to being able to plan, monitor and evaluate their own learning. This can have a significant impact not only on academic success but also in social relationships and emotional responses to unfamiliar situations. Throughout our Decipha programmes we set a high premium on students developing these skills. This can take place through our bespoke reading and literacy programmes and through the process of developing a person Centred Plan. Decipha Solutions is a programme that specifically uses a solution focussed approach to help young people to frame preferred futures.

Decipha Reading and Literacy

Our unique online literacy intervention called 'Decipha reading' is based on evidence that children with reading problems and dyslexia often struggle with tasks that involve working memory and processing, but have relative strengths in knowledge and facts.

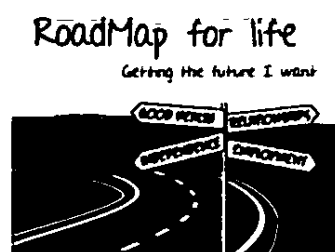
Children become Time Agents and travel through time and space in their password protected online dashboard, learning about different historical periods - for example they find out why pyramids were built, hide in a bomb shelter during the Blitz, escape from dangerous dinosaurs 250 million years ago and go into space with Neil Armstrong. At the same time they follow a very structured synthetic phonics programme which helps them to develop the skills to read and write.

Published research suggests that the best way to learn to read is 'little and often' in regular bursts, so the programme is delivered in 20 minute sessions three times a week at school and once at home by carer's. The reading specialist is at hand to answer any problems that arise that can be mentioned in the child's blog (Rose Report¹⁶ 2006 and 2009).

The Decipha Programme formed part of the 'Include Duchenne' Project which won the 2011 National Lottery Best Education Project. It was run as a research project with the Centre for Child Research University of Swansea.

¹⁶ Rose, J. Independent Review of the teaching of early reading: final report. Department of Children, Schools and Families 2006.

Rose, J. Identifying and Teaching children and young people with dyslexia and literacy difficulties: an independent Report from Sir Jim Rose to the Secretary of State for Children, Schools and Families. Department of Schools, Children and Families 2009.



Decipha Solutions - personalised outcomes building on success

The Decipha team can provide a solution focussed approach to working with young people and their families where the young person might be experiencing bullying, explosive behaviour, poor social and communication skills or at risk of exclusion from school. We are looking for personalised outcomes and by focusing on what works well with pupils and building on success as the framework for support.

The majority of what we all learn comes from conversations. During this process at home, school, in our community or at work we define ourselves and begin to grasp our role. If we can't find our voice, can't communicate, we feel at a loss and perhaps our world is then defined by others often with disastrous consequences.

Questions lie at the heart of the Brief coaching method. Our solution focussed approach is based upon the young person "telling" him or herself how to reconstruct their own world in a way that can make a difference. The questions we use at Decipha Solutions are a provocation to the young person to think differently.

Many young people that we have worked with have lagging cognitive skills that can be a significant barrier to young people finding their voice. At Decipha we have developed an lagging skills list that helps to identify young people with Difficulty handling transitions, shifting from one mindset or task to another (shifting cognitive set), Difficulty doing things in a logical sequence or prescribed order or Difficulty persisting on challenging or tedious tasks for example.

Traditionally these lagging skills are associated with ADHD, ASD, Autism, Dyslexia, OCD, poor speech and language or even poor motor co-ordination. While these diagnosis of a condition can be useful in terms of labelling the problem it does not always help in terms of recognising what young people or their families can do and what aspirations they might have for the future. Our approach is to look forward from the label towards preferred futures.

We can offer an initial 10 - 16 hour programme of 2 hour intervention slots that would last for a term. Although we often work with one individual we would expect that through our final evaluation that sustainable steps are agreed that will be in place to continue to support the child. We ask for a school senior manager or year head to be involved so that there is the opportunity to discuss implications for the school community as a whole.

All meetings and discussions are conducted in strictest confidence and bound by Decipha's Child and Adult protection policies¹⁷

¹⁷ <http://www.decipha.org/policies/archive>



Our teams expertise has been built upon meeting the needs of young people with complex medical, learning and behaviour problems for conditions such as Duchenne Muscular Dystrophy We have many years experience working in London schools as Inclusion managers, SENCO's, PRU's and as learning support teachers

The Philosophy and practice of Decipha Solutions is influenced by the 'collaborative problem solving' approach of Dr Ross Greene, author of 'The Explosive Child' and 'Lost at School' and in the UK, Solution focussed Brief Therapy¹⁸ Decipha staff have all undertaken coaching courses with UK Brief in London who provide us with ongoing professional support and supervision

Events and Activities by Region

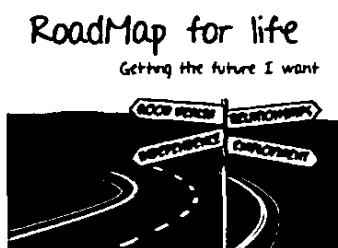
Table 2 Events and Activities by Region

	Decipha Community Interest Company Activity	Region
June 2013	Presentation in Stormont on Transition issues to MLA's and families from Northern Ireland	Northern Ireland
June 2013	Free learning and behaviour workshop for families in Belfast supported by Action Duchenne	
June 2013	Access Arrangements Assessments at Buxton School	London
June 2013	Work with consultant Physiotherapist GOSH and Karate Sensei to develop programme of martial arts for neuromuscular conditions	London
June 2013	Presentation at Welsh Assembly on Transition Issues and Disability	Wales
May 2013	Decipha Literacy Assessment	East Midlands
May 2013	Action Duchenne National meeting in Hereward Coventry – talk to meeting about Decipha work and support available for families living with Duchenne	
May 2013	Duchenne Professional Training on Learning and Behaviour issues in Duchenne for 15 professionals from special schools, secondary schools, local authorities, Europe, hospices	London
April 2013	Work with Professor Angela Fawcett to develop resources for overlapping conditions	London

¹⁸ Research published by Dr Ross Greene for his Collaborative Learning methods and assessment of lagging skills www.livesinthebalance.org and Brief Therapy Training www.brief.org.uk



April 2013	London Brokerage Accredited Training to be able to support families to get funded support for independent living	London
April 2013	Janet Celine and Nick completed training with National Development Team Inclusion – Person Centred Planning to support delivery of PCPs with families and schools	London
April 2013	Care NMD conference Budapest Hungary Dr Janet Hoskin attended this event	
April 2013	Participation in the Sexuality working alliance group Milton Keynes OU – developing sexuality care pathway for adults with life-limiting conditions	Midlands
March 2013	Attendance at APPG on Disability and Education with Edward Timpson Secretary of State for Children and Families on implications of new SEND legislation for families and young people with Life Limiting conditions	London
December 2012	Training for Access Arrangements Communicate -Ed	London
November 2012	Action Duchenne International Conference – delivered Decipha workshop for parent and professionals on Learning and Behaviour in Duchenne and Dr Janet Hoskin presented results from Include Duchenne research project	London
June 2012 – June 2013	Decipha Literacy Assessments (2)	Northern Ireland
	Decipha Literacy Assessments (4)	South West
	Decipha Literacy Assessments (3)	South East
	Decipha Literacy Assessments (4)	London
	Decipha Literacy Assessments (2)	East
	Decipha Literacy Assessments (3)	North East(Yorkshire)
	Decipha Literacy Assessment (1)	North West
	Decipha Literacy Assessment (1)	Midlands



5. Our Social Impact in Numbers

96% of parents reported improved understanding of their child's learning needs as a result of the Decipha baseline assessment that formed an essential part of the Literacy project

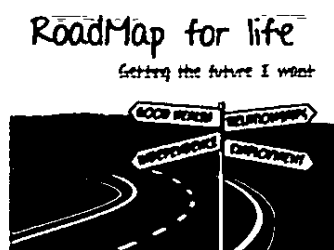
81% of schools also reported an improved understanding of the needs of young people with a complex condition like Duchenne 69% of schools noted that they had changed the way that they were now working with the children

100 families with Duchenne Muscular Dystrophy have been sent a full assessment and report for their child's learning and behaviour since 2008 that has successfully impacted upon the individual achievements of these young people

75 young people with Duchenne Muscular Dystrophy have undertaken the Decipha Literacy programme and the results show that

- Lower Juniors (7-8 year olds) improved their single word reading age by 2 years (6yrs 6m to 8yrs 6m) following the Decipha Reading programme(Dr Janet Hoskin published PhD Thesis 2011)
- 1 year 2months improvement in single word reading for all pupils following Decipha Reading programme n=34 (Dr Janet Hoskin published PhD Thesis 2011)
- 3 years 1 month improvement in text reading following Decipha Reading Programme n=34(Dr Janet Hoskin published PhD Thesis 2011)
- 69% pupils said they felt better about themselves, 72% parents reported improved self esteem, 78% schools reported improved self esteem following Decipha Reading programme(Dr Janet Hoskin published PhD Thesis 2011)
- 100% of parents , 88% young people, 82% schools reported improvement in reading, writing and literacy skills following Decipha Reading and literacy programme(Dr Janet Hoskin published PhD Thesis 2011)
- Decipha Reading Programme Effect sizes - 1.4 timed Reading, 0.4 Spelling, 1.1 Phonics, 0.4 single word reading standardised score, 0.6 verbal recall processing memory skills, 0.5 visio spatial short term memory, 0.7 Comprehension, 0.6 text level reading standardised score(0.2 indicates a small effect, 0.8 is a large effect size)(Dr Janet Hoskin published PhD Thesis 2011) n=34)

80 Health and Education and Social Care Professionals attended 3 workshops in 2012 sponsored by the national Charity The Muscular Dystrophy Campaign The feedback was overall very positive on the presentations concerning the specific education and health needs for children living with a Muscular Dystrophy Delegates reported that it was very useful to understand the links between neuro developmental conditions



20 Health and Education professionals rated our one day Conference on Learning and Behaviour in Duchenne Muscular Dystrophy in 2013 as excellent from across the UK and Europe

16 families attended workshops in Hospices at Richard House Newham London, Acorn Hospice in Birmingham and Worcester

Training, Seminars and consultation with Neuromuscular Centres at Great Ormond Street London and Newcastle

In 2006 members of the Decipha team edited the Behaviour and Learning toolkit for Duchenne Muscular Dystrophy that has been used by over 800 schools and families

From 2008 to 2011 Dr Janet Hoskin consulted with over 95 young people living with Duchenne Muscular Dystrophy and their families and more than 100 schools in the process of designing and delivering a unique online literacy and reading programme for young people with a complex medical condition Janet published the results of the impact of this intervention in a PhD thesis validated by the University of Swansea, Wales

In terms of near transfer skills 88% of the children, 100% of parents and 80% of schools reported that reading and/or writing had improved as a result of the Decipha Literacy programme

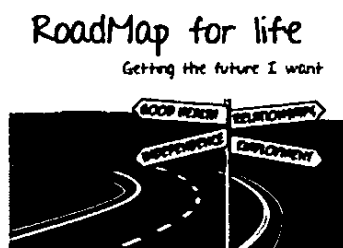
6. Achievements and Awards

In 2011 the Decipha Reading programme won the National Lottery Award for best education project

Results for this project are about to be published in the British Journal for Special Education

All members of the Decipha Team have been trained by Brief <http://www.brief.org.uk/> to undertake coaching using Solution focussed therapy and approaches The team are supervised on a quarterly basis by the Brief Therapy Team

Members of the Decipha team have been trained by Dr Ross Greene in the use of his Collaborative Problem Solving approach <http://www.livesinthebalance.org/> to working with Children who experience neuro developmental delay



Decipha Team members are certified Brokerage Agents through The London Brokerage network to undertake self directed support for using individual budgets and so improving the life chances of disabled people

The Decipha team has been trained by the National Development Team for Inclusion (NDTI) in the use of Person Centred Planning tools

Dr Hoskin and Celine Barry are members of the Apprenticeship Disability Reference group BIS/DFE Apprenticeships Unit at the Department of Business and Skills and DfE

Dr Hoskin is a member of the steering Committee of Taking on and Taking Over (TOTO) looking at the Care and support arrangements for physically disabled young adults at the social policy research unit York University

Dr Hoskin and Celine Barry are members of the Sexuality Alliance for people with life limiting conditions at the Open University in partnership with "Together for Short Lives" To identify key issues about sex and sexuality for life limiting conditions

Dr Hoskin is a participant in the European Care NMD network

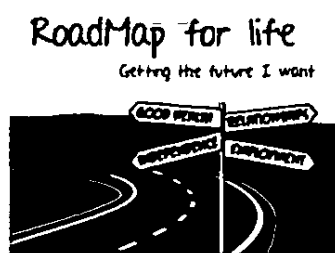
Nick Catlin was recently the member of the Scientific Advisory Board for the MDEX research consortium that was set up to discover new drug therapies for neuromuscular diseases

Nick is a member of the TACT Committee for Treat NMD

Nick Catlin established the first patient Registry for Duchenne Muscular Dystrophy in the UK and is a member of the Steering group for Patient Registries

7. Consultation with Stakeholders

"The Decipha team has assessed a Year 3 pupil at St Columba's P S who has Duchenne Muscular Dystrophy Last November Celine Barry visited our school to train his classroom assistant, Margaret and his mother in how to implement the Decipha Reading and Literacy programme I observed at first hand Margaret working with our pupil and I was very impressed with his enthusiasm for and engagement in the programme"



It transported him on exciting adventures around the world. When he was re-assessed in June by Celine, seven months after he had commenced the programme, he had made excellent progress in his reading and his skills in blending and segmenting were developing well. His self-esteem has greatly improved and he has a much more positive attitude to school. As principal and SENCo, I feel that the Decipha Reading programme has the capacity to not only help children with DMD but also to make a difference in the life of any child who has learning difficulties in literacy. Having witnessed the difference that it has made, I now intend to purchase the licence to implement the programme with targeted pupils in our school with literacy difficulties and working memory problems." **Collette Maguire Principal St Columba's Primary School Clady Northern Ireland**

Through the delivery of our services Decipha is in direct contact with a number of key stakeholders of our Community and we have continually asked for feedback through questionnaires, workshops and Conferences (See Section 2 of this report)

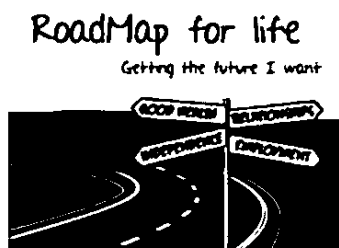
From 2008 to 2011 Dr Janet Hoskin consulted with over 95 young people living with Duchenne Muscular Dystrophy and their families and more than 100 schools in the process of designing and delivering a unique online literacy and reading programme for young people with a complex medical condition. Janet published the results of the impact of this intervention in a PhD thesis validated by the University of Swansea, Wales

"As far as Decipha is concerned it has been something of a revelation. Fraser simply did not get reading and writing before Decipha and suddenly it began to make sense to him. At times he has found it difficult but it has always given him a sense of achievement. He has made a great deal of progress and this has been recognised at school and they have been very supportive. Fraser can now make a decent attempt at reading almost anything. We had wondered if he would ever be able to read so this is amazing. It will certainly enrich his life."

Julia Carr, mother of Fraser aged 10 years diagnosed with Duchenne muscular dystrophy and Autism. Whickham, Gateshead.

University of Swansea reported that 96% of parents reported improved understanding of their child's learning needs as a result of the Decipha baseline assessment that formed an essential part of the Literacy project. 81% of schools also reported an improved understanding of the needs of young people with a complex condition like Duchenne. 69% of schools noted that they had changed the way that they were now working with the children.

In terms of near transfer skills 88% of the children, 100% of parents and 80% of schools reported that reading and/or writing had improved as a result of the Decipha Literacy programme.



Through our partnership with the National Charity Action Duchenne Decipha continues to assess and offer bespoke interventions for young people with Duchenne. This involves consultation with parents, school Head teachers and SENCO's and the young people themselves on how to best meet their complex learning needs. Decipha produces regular reports to the Trustees of the Charity Action Duchenne on the impact of its programme to meet learning and behaviour needs.

Decipha has delivered workshops in partnership with the National Charity The Muscular Dystrophy Campaign. Three workshops in 2010-11 in Exeter, Loughborough and Leeds were attended by 80 education and health professionals who currently work with young people with a complex medical condition.

Members of the Decipha team work with the Family Planning Association to deliver "Let's Talk about Sex" workshops for young disabled people with life limiting conditions.

Dr Janet Hoskin has informed and attended an international Conference in Hungary in April 2013 that discussed the findings of Care NMD's in depth consultation with patients.

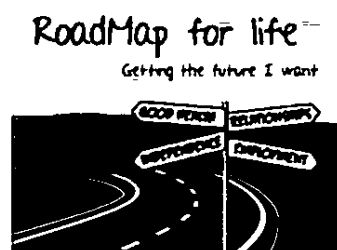
The Decipha team works with Hospices in the North East, London, Midlands, South East and South West to develop bespoke Transition interventions for young disabled people with life limiting conditions and their families.

We are developing partnerships with Neuromuscular Centres of Excellence to formulate support for Transition (14 -19) at meetings in 2013 -14.

"Decipha has started to work with young adults like my son Jonathon who is now 23. Jon went to University but despite some ill health he would very much like to get more involved with work guiding other young people who are living with Duchenne Muscular Dystrophy. We will all be supporting Decipha to help them to develop new programmes that can help young people like Jon to find work and to participate more in society and their local community." **Angela Stringer London**

Members of the team coach and mentor person Centred Plans for young people.

Celine Barry is a Tutor and Mentor for SENCOs on the National Award for SEN Co-ordination and mentor for SENCOs for the National Award for SEN Coordination in London.



8. Lessons Learned

The 3 year consultation and intervention with Duchenne Muscular Dystrophy and other stakeholders with complex medical conditions has flagged up a number of key issues

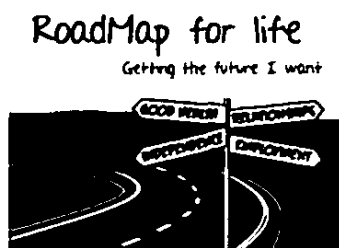
There is a high level of need for good information, advice and guidance to support young people and their families to take control of their education health and care. Despite current changes in legislation surrounding personal budgets key information to help young people develop independence is still missing particularly for those with the most complex needs.

It is important for Carers and Parents to understand at some level that complex medical conditions like Duchenne Muscular Dystrophy have a high risk of co-occurring neuro-developmental disorders. This is also true of conditions like dyslexia, autism, ADHD, OCD for example. Making provision for the progressive loss of physical function is important in terms of access to school and the local community. But Decipha discovered that learning and behaviour problems that can be the result of a neuro-developmental disorder related to the condition are going largely unrecognised. When we have been able to feedback to Carers and Parents via our in depth assessments then progress can be made in tackling some of the underlying problems. This education and training process needs to be developed further and build training for school and health professionals.

The lack of awareness can be expected as Duchenne and other Muscular Dystrophies for example are rare conditions and schools are unlikely to have had much experience of these young people. For Parents and Carers this is often a completely new and unexpected condition that they will have to face for the life of their child.

The emotional and social problems for Carers can run deep and little seems to have been done to support families in making positive plans for the future. Charities like Action Duchenne and the Muscular Dystrophy Campaign have good online information available but there is not always the opportunity to really get to grips with some of the complex issues. Young people themselves have reported to us the problems with transitions in particular in KS2, KS4 and into adulthood. Young people remain the objects of reviews and planning rather than them being able to take a lead and becoming the centre of the transition process.

As young people move into adulthood many medical and educational services seem to disappear. This can be physiotherapy, respiratory and heart care management. There is little preparation for young people to be able to take control of their medical condition and request key services and support.



Young men are living longer with better medical management of life limiting conditions but further and higher education and work opportunities remain very poor. This is evidenced by comprehensive research in Care NMD and Abbott and Carpenter (2010) for example. There is a real need for the community to be able to develop good role models for younger people and their families who are living with conditions like Duchenne Muscular Dystrophy. At Decipha we will be exploring how we can further involve adults as ambassadors and supporting new initiatives and projects that have adult users on steering committees.

9. Plans for the Future

Decipha will continue to provide services and support for Young people and families with long term complex medical conditions. We will build on our expertise gained from projects with Muscular Dystrophy.

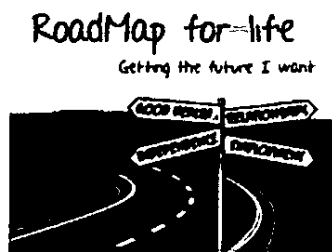
Decipha will continue to offer learning and behaviour assessments that can help to pinpoint key needs for young people with lagging cognitive skills.

Decipha will continue to research and assess the needs of those with complex medical conditions and develop projects and interventions based on evidence that can make a difference to the quality of these young people's lives.

The Government Green paper for SEN is very likely to result in future changes to the way needs are assessed and met. In particular there will be one plan to meet Health, Education and Care needs that will largely replace the current SEN Statement. Decipha will develop programmes and resources to enable this change to be implemented to ensure the best possible outcomes for young people and their families who have complex medical and special educational needs. There will be an important need for training professionals on changes in legislation and how to bring in personalisation and meeting aspirations for young people who have life limiting or complex needs and also support work to SLTs and LA's who are restructuring their provision.

10. Concluding Comments

Decipha is providing much needed specialist assessment and support for young people with rare genetic conditions like Muscular Dystrophy.



The changes to how special needs assessments will be undertaken by embracing a person centred planning approach to meet long term health and educational needs will mean that the aspirations of families and young people will be now be considered in a more focussed way. This process in turn will require further training and support for families and those professionals responsible for executing life plans to ensure that the process is followed and resources are in place to meet identified needs

Young people with life limiting conditions are living longer due to better diagnosis and long term medical care At Decipha we are in a unique position to be able to offer projects and resources to help young people to take advantage of this longer life expectancy and seize real opportunities for becoming fully engaged citizens

11. Summary of Accounts

Decipha CIC major grant income for 2012-13 came from the National Charity Action Duchenne This enabled Decipha to be able to undertake assessments for young people living with Duchenne Muscular Dystrophy

During this financial year Decipha relocated to new offices at CAN Mezz in Old Street London and this new rental cost enabled the organisation to have office space within a complex for other social enterprise organisations and the free use of meeting and conference rooms We have now established contact with other social enterprise groups that have provided very useful support and information

Computer costs remain the same for hosting our Decipha Reading programme and our website