Developmental Practitioners Association-

Therapy Outcomes Measures (TOMs)

Handbook

May 2024

Booklet 1 of 2 – Booklet 2 Assessment Guidance

Therapy Outcome Measures Developed Scale for Uninhibited Primitive Reflexes in line with the principles detailed in: Enderby P & John A (2015) *Therapy Outcome Measures for Rehabilitation Professionals, 3rd Edition Guildford: J&R Press.*

CONTENT

1. Forward

It's great to know that the DPA has got approval from Professor Pam Enderby for the inclusion of Uninhibited Reflexes Developed Scale in the Therapy Outcomes Measures (TOMs).next edition.

This is great news for those of us that work in neurodevelopment as we now have a simple tool to measure our successes with our clients in a statistically significant way that is recognised by wider health, social and education services. This means that we now can collate evidence from a range of practitioners and show the positive outcomes of our work.

This is something that we have been exploring for some time, and I am very grateful to the DPA members who have given so much time and energy to make this happen. Sara O'Donnell has done a tremendous job in training DPA members in TOMs and Pete Griffin has put a huge amount of work in pulling the information together and keeping the TOMs Steering Group in order! Thanks also to: Gill Brooksmith, Suzanne Roberts, Janet Glover and Viv Hailwood for all their contributions and insights.

I look forward to our continued work with TOMs as we use it to build a body of evidence that shows the importance of reflex integration work.

Janice Graham

DPA Chair

January 2024

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2. Introduction

a. Why the booklet?

This booklet is the outcome of nearly two years of work by the members of the TOMs steering committee, who have worked at creating a Developed TOMs scale for Uninhibited Primitive Reflexes. In that time, the Developed scale has been trialled and revised over eleven times to produce a set of criteria designed to support fellow members of the Developmental Practitioners Association in their assessment of the effectiveness of their primitive reflex therapy. Some DPA members have undergone TOMs training and hopefully will find that the Developed scale better enables them to make clearer judgements. Whether or not you are familiar with TOMs the DPA can offer support and training.

b. What is TOMs?

Therapy Outcome Measures is a precise and well-established methodology for measuring the impact of intervention across the four domains described by the World Health Organisation's International Classification of Disability and Function(WHO, ICF 2001) namely:

1. Impairment: the underlying condition[1]
2. Activity: ability to complete daily activities[1]
3. Participation: social participation[1]
4. Wellbeing; emotional health[1]

[1]Enderby P & John A (2015) *Therapy Outcome Measures for Rehabilitation Professionals, 3rd Edition Guildford: J&R Press*

It is:

- A relatively simple, effective method for assessing the outcome of any therapy.
- Uses four domains so that you get a picture of the whole person.
- Allows cross disciplinary comparisons.
- Helps us to provide a good service by 'measuring, collecting data and contributing to the evidence base' (CCG NHS guidance
- Already widely used and widely accepted.
- Cited in the NHS Commissioning Guidance for Rehabilitation https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf appendix 6.6

c. Why a Developed Scale?

Those members who have undergone TOMs training will be familiar with the TOMs Core scale which is a 'one size fits all' scale across a wide range of interventions and therapies. The Developmental Practitioners Association is a broad church of therapies, methodologies, and disciplines, the majority of which, at least in some part, have a focus on better enabling clients to integrate their Primitive Reflexes. The 'one size fits all' core scale would seem to be an ideal tool, so why bother to develop a Developed scale? It was felt that by developing a specific Developed scale we:

- would have greater commonality of language and understanding between the very differing approaches that have Primitive Reflexes as their focus.
- build stronger networks within the association and give the Association a stronger profile and identity.
- better raise the profile of Primitive Reflex Therapy by having a specific scale included in a book commonly used and valued by health professionals.
- would be better able to make judgements about the outcomes of our individual practice and share those outcomes with other like-minded supportive members.
- would be better able to collect, collate and publicise data about the efficacy of Primitive Reflex Therapies by encouraging members to participate in a formalised DPA Research Team(DPARN).
- would contribute to the growing evidential research about the efficacy of Primitive Reflex-based therapies.

e. How reliable is the Developed Scale?

Intra - Rater Reliability – the degree of agreement by the same rater upon repeated scoring of the same case studies over time

Most of those members who have undergone TOMs training have to some extent established that they have intra-rater reliability. However, it would be preferable to revisit and practice with the Uninhibited Primitive Reflex Developed Scale and case studies that directly relate to our practice. The DPA will offer this opportunity to members both new to TOMs and those who have had previous experience.

Inter-Rater Reliability – the degree of agreement, using the Developed Scale, across several raters looking at the same case studies. The TOMs working party have each looked at 11 case studies and analysis shows that there was 94% Inter-Rater Reliability. As the Developed scale becomes more widely used, we will have a better picture of Inter-Rater Reliability.

f. Why Join the DPA Research Network (DPARN)

You do not have to join DPARN. Provided you have had TOMs training you can use TOMs and the Developed Scale for your own individual purposes and other alternative therapies. Those joining DEPARN will benefit from:

- regular support, training, and updates;
- a moderated case study pack made available;
- surety of judgement through moderation;
- contributing to a larger scale research project that will show the outcomes of Primitive Reflex Therapy;
- Moodle online quiz;
- annual membership certification;
- acknowledgement of contribution in any future research publication.

3. Uninhibited Primitive Reflexes: Developed Scale -

Include all the primitive reflexes initially considered.

Profound		Severe		Severe/Moderate		Moderate		Mild		Normal Limits	
0	0.5	1	1.5	2	2.5	3	3.5	4	4.5	5	
Impairment – Uninhibited Primitive Reflexes	**0 Profound:** Some primitive reflexes **may not be evident,** or **they are all fully uninhibited**. **81-100%** fully or almost fully uninhibited **All** Postural reflexes **totally underdeveloped**.										
	1 Severe: A **significant majority** of primitive reflexes are **fully or almost fully uninhibited**. **61 -80%** fully or almost fully **uninhibited**. **Most** Postural reflexes are **totally or mostly underdeveloped.**										
	2 Severe/Moderate: Around half of the primitive reflexes are **fully or almost fully uninhibited**. **41-60%** fully or almost fully **uninhibited**. **Some** Postural Reflexes **may be developing.**										
	3 Moderate: Many primitive reflexes are **partially inhibited.** **21-40%** fully or almost fully **uninhibited.** **Many** postural reflexes are **developing/fully developed.**										
	4 Mild: Nearly all primitive reflexes are almost **partially or fully inhibited.** 1-20% fully/almost fully **uninhibited**. **The majority** of postural reflexes are **developed/developing.**										
	5 No Impairment: All primitive **reflexes are fully inhibited**. **0% uninhibited**. **All** postural reflexes are **fully developed.**										
Activity / Independence	0 No purposeful active movement, totally dependent, requires full physical care and constant vigilance/supervision.										
	1 Assists/Co-operates but the burden of the task falls on professional/familiar carer.										
	2 Can undertake some part of the task but needs a high level of support to complete.										
	3 Can undertake task function in familiar situations but requires some verbal prompting/physical assistance.										
	4 Requires some minor assistance occasionally or extra time to complete a task.										
	5 Independent/able to function.										
Social Participation	**0** No autonomy, isolated, no social/family role.										
	1 Very limited choices, contact mainly with professionals/familiar carers, no social or family role, little control over life.										
	2 Some integration, value, and autonomy in one setting.										
	3 Integrated, valued, and autonomous in a limited number of settings.										
	4 Occasionally some restriction in autonomy, integration, or role.										
	5 Integrated, valued, occupies appropriate role.										
Wellbeing	**0** High & constant levels of concern/anger/severe depression or apathy, unable to express or control emotions appropriately.										
	1 Moderate concern, becomes concerned easily, requires constant reassurance/support, needs clear/tight limits and structure, and loses emotional control easily.										
	2 Concern in unfamiliar situations, frequent emotional encouragement and support required.										
	3 Controls emotions with assistance, emotionally dependent on some occasions, vulnerable to change in routine, spontaneously uses methods to assist emotional control.										
	4 Able to control feelings in most situations, generally well-adjusted/stable (most of the time/ most situations), occasional emotional support/encouragement needed.										
	5 Well adjusted, stable, able to cope with most situations, opportunity to self-analyse, accepts and understands own limitations.										

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4 TOMs Primitive Reflexes Equivalence table

Some practitioners use criterion-referenced scoring when assessing their clients. Some have a 10-0 scale with 10 being 'fully uninhibited' and 0 being 'fully inhibited. Others use a 4-0 range with 4 being fully uninhibited and 0 being fully inhibited. Below is an Equivalence Table. Whatever methodology is used ~~to~~ decide on the level of impairment, it is **'best fit'** based upon the information you have at that time. Later, information may become known which may prompt you to alter your initial judgement.

TOMs Descriptor	TOMS Score	Percentage of Fully Almost Fully Uninhibited Primitive Reflexes	Primitive Reflex descriptor	Criterion-Referenced 10-0 scale	Criterion-Referenced 4-0 scale
Profound	0	100-81%	Fully Uninhibited	10	4
	0.5			9	3.6
Severe	1	80 -61%	Almost Fully Uninhibited	8	3.2
				7.5	3
	1.5			7	2.8
Severe/ Moderate	2	60-41%	Partially Uninhibited	6	2.4
	2.5			5	2
Moderate	3	40=21%	Partially Inhibited	4	1.6
	3.5			3	1.2
				2.5	1
Mild	4	20-1%	Almost Fully Inhibited	2	0.8
	4.5			1	0.4
No Impairment	5	0%	Fully Inhibited	0	0

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5. Question Prompts

You may want to develop a questionnaire so that you can come to a judgement about Activity, Social and Well-being. There are always issues about misinterpretation even with professionally written questionnaires, so the steering party has shied away from this, preferring to question clients in person. However, the following prompts might help you to schedule your questioning and arrive at a 'best fit' judgement.

Activity and Independence - My child is as independent as their peers. Consider things such as age-appropriate washing, dressing, feeding, toileting, independent learning, and dependency upon others.

0 - There is a profound difference between my child and their peers
1 - There is a very significant difference between my child and their peers
2 - There is a significant difference between my child and their peers
3 - There is a moderate difference between my child and their peers
4 - There is only a small difference between my child and their peers
5 - There is no real difference between my child and their peers

Social Participation - My child is as socially able as their peers. Consider age-appropriate social engagement in terms of play, conversation, participation, clubs etc in different settings.

0 - There is a profound difference between my child and their peers
1 - There is a very significant difference between my child and their peers
2 - There is a significant difference between my child and their peers
3 - There is a moderate difference between my child and their peers
4 - There is only a small difference between my child and their peers
5 - There is no real difference between my child and their peers

Well Being - My child can emotionally regulate as well as their peers. Consider age-appropriate emotional control, fears, confidence, and self-awareness in a variety of settings.

0 - There is a profound difference between my child and their peers
1 - There is a very significant difference between my child and their peers
2 - There is a significant difference between my child and their peers
3 - There is a moderate difference between my child and their peers
4 - There is only a small difference between my child and their peers
5 - There is no real difference between my child and their peers

6. How Many Primitive Reflexes?

Primitive reflexes *- involuntary motor responses originating in the brainstem present after birth in early child development that facilitate survival. https://www.ncbi.nlm.nih.gov/books/NBK554606/. In normal development the primitive reflexes become inhibited as the postural reflexes develop and cortical control strengthens.*

Uninhibited Primitive Reflexes *–The continued activation of the primitive reflexes and continued deactivation of the postural reflexes beyond the age of 3 years*.

We have chosen the phrase *Uninhibited Primitive Reflexes* rather than the more commonly used terms *Retained/Unintegrated/Active Primitive Reflexes.* Our view is that *Uninhibited and Inhibited* better describes the process of the primitive reflexes emerging in- utero, supporting the birth process, enabling the newborn to survive and develop. As frontal lobe control and postural reflexes evolve, they override or *inhibit* the primitive reflexes. The primitive reflexes remain *inhibited* throughout life, unless there is a diminution in frontal lobe control and the postural reflexes, perhaps due to physical or mental trauma, disease or aging. Primitive Reflexes may then, as a protective mechanism, become yet again *uninhibited* and function to help sustain life.

There is quite a lot of research supporting the view that uninhibited primitive reflexes are associated with learning difficulties associated with sensory-vestibular disorders. However, there is limited empirical data that measures the efficacy of therapies that are purported to help the individual better inhibit their primitive reflexes. This is the motivation to set up the DPA Research Network.

How many primitive reflexes should I assess?

It may only be possible to assess a few primitive reflexes, but sufficient needs to be assessed for the practitioner to come to a comfortable judgement about the overall level of impairment. Remember it is a '**best fit'** judgement. In the INPP school programme for instance, only three primitive reflexes are assessed. So long as the same primitive reflexes assessed at the start of your programme are assessed at the end that is fine. As you work through your programme you may gather greater insights that would alter your initial judgement. You should adjust your initial assessment accordingly. **IT IS YOUR JUDGEMENT OF THE BEST FIT**. Some members of the TOMs Steering Committee are available to advise. In addition, those joining the DPARN will have a battery of moderated case studies to refer to.

Below is a list of primitive reflexes commonly referred to in literature. The list, however, is not exhaustive.

Fear Paralysis	Intrauterine
Moro	Primitive
Asymmetrical Tonic Neck	Primitive
Tonic Labyrinthine	Primitive
Symmetrical Tonic Neck	Primitive/Transitional
Spinal Galant	Primitive
Rooting	Primitive
Suck	Primitive
Palmar	Primitive
Plantar	Primitive

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Babkin	Primitive
Babinski	Primitive
Oculi Head Righting Reflex	Postural
Labyrinthine Head Righting	Postural
Segmental Roll	Postural
Landau	Transitional
Amphibian	Postural

7. Why Two Impairments?

For research purposes it is preferable if we look at two impairments:

a. Uninhibited Primitive Reflexes;
b. What you consider to be the Impairment 2.

The reason for this is that we want to see if there is a link between uninhibited primitive reflexes and a range of challenges. For example, as the primitive reflexes integrate does emotional regulation improve. We must measure both to be able to measure two impairments to answer such questions.

To include more than two impairments would probably make the process unnecessarily time consuming and unwieldy. It is up to you to choose the Impairment 2, but with a view to keeping the data base manageable and being able to pool information from a number of practitioners we would initially at least that we stick to broad 'brush stroke' categories.

Firstly, we have chosen the four SEND Code of Practice categories.

a. Communicating and interacting.
b. Cognition and learning.
c. Social, emotional and health difficulties.
d. Sensory and/or physical needs.

There are two additional categories, where the client has a diagnosis of:

e. Diagnosed Special Educational Need
f. Diagnosed medical condition.

*a. Communicating and interacting.**

'Children and young people with speech, language and communication needs (SLCN) have difficulty in communicating with others. They may have difficulty with one, some or all of the different aspects of speech, language or social communication at different times of their lives. This area includes those children and young people with an autistic spectrum disorder who also are likely to have difficulties with social interaction, and with language, communication and imagination, which can impact on how they relate to others.

Some pupils with autism need an easily understood environment with a low level of distraction and sensory stimulus to reduce anxiety or distress. They may need a safe place to calm down and may benefit from having access to a safe, sheltered, outdoor space.

b. Cognition and learning.*

Learning difficulties cover a wide range of needs, including moderate learning difficulties (MLD), severe learning difficulties (SLD) - where children are likely to need support in all areas of the curriculum and have associated difficulties with mobility and communication - through to profound and multiple learning difficulties (PMLD). Children with PMLD are likely to have severe and complex learning difficulties as well as a physical disability or sensory impairment. This range of needs also includes specific learning difficulties (SpLD) which encompasses a range of conditions such as dyslexia, dyscalculia and dyspraxia.

Pupils who have these needs may need additional support in the classroom or in a smaller quiet place. They may use specialist equipment.

c. Social, emotional and health difficulties.*

Children and young people may experience a wide range of social and emotional difficulties which manifest themselves in many ways. These may include becoming withdrawn or isolated, as well as displaying challenging, disruptive or disturbing behaviour. These behaviours may reflect underlying mental health difficulties such as anxiety or depression, self-harming, substance misuse, eating disorders or physical symptoms that are medically unexplained. Other children and young people may have disorders such as attention deficit disorder, attention deficit hyperactive disorder or attachment disorder.

Pupils who have these needs may need extra space to move around and to ensure a comfortable distance between themselves and others. They may need to be able to withdraw from their group, possibly to a sheltered outdoor area. Some may take extreme risks or have outbursts and need a safe place to calm down. Some may need behaviour support or counselling which should take place in a quiet supportive environment.

***d. Sensory and/or physical needs**.**

Some children and young people require special educational provision because they have a disability which prevents or hinders them from making use of the educational facilities generally provided in a mainstream setting. This includes pupils with visual impairment (VI), hearing impairment (HI) or a multi-sensory impairment (MSI) who are likely to require specialist support and/or equipment to access their learning or facilitation support. It also includes those with a severe physical disability (PD).

Some pupils with sensory impairments may need extra space and additional 'clues' to help them negotiate their environment independently. Pupils with physical disabilities may use mobility aids including wheelchairs, standing frames, or horizontal learning stations, all of which can be bulky and require storage. Whether they are able to move around independently or need support, there should be sufficient space for them to travel alongside their friends. Accessible personal care facilities should be conveniently sited. Many will need specialist support (for example mobility training or physiotherapy).

*SEND Code of Practice 2015

e. Diagnosed SpLD

The extent to which a Specific Learning Difficulty, diagnosed by a qualified practitioner, impacts upon the individual . If the client has a diagnosis, such as Dyslexia or ADHD and you are confident, from the information available, to make a judgement about the severity of that condition, then that should be your Impairment 2. If you are not confident, either seek advice or look at the most severe aspects of the condition and classify it in one of other categories. You may find the 'Behaviour Checklists' (Appendix E) useful.

f. Diagnosed Medical Condition

The extent to which a specific diagnosed medical condition impairs the individual compared to their peers.

These are very broad, 'brush stroke' categories and over time, as more data becomes available or we feel the need to drill down deeper we may have to include new categories or different subcategories. To do this we may have to revisit you to gather more detailed information if it is available. The Comment Box on the Data Sheet is one place where you can record additional important information.

We may be able to drill down deeper. For instance poor age appropriate 'fine motor control' is a common feature amongst individuals with Developmental Coordination Disorder. If inhibiting the Primitive Reflexes can be shown to improve handwriting, pencil control . using scissors, handling cutlery etc then this could be an item for its own research.

It is strongly advised that the assessments would be more consistent if the TOMs Core Scale is used for any Impairment 2. The Activity, Social Participation and Well Being domains are exactly same for both the Uninhibited Primitive Reflexes and Impairment 2.
The *Therapy Outcome Measures, User Guide and Scales does include* some developed scales that relate to some of the Impairment 2s. but it would more consistent if we all used the same Core Scale. Following

8. Core Scale

Profound		Severe		Severe/Moderate		Moderate		Mild		Normal Limits	
0	0.5	1	1.5	2	2.5	3	3.5	4	4.5	5	
Impairment –	**0** The most severe presentation of this impairment										
	1 Severe presentation of this impairment										
	2 Severe/moderate presentation of this impairment										
	3 Moderate presentation										
	4 Just below normal/mild presentation										
	5 No impairment										
Activity / Independence	0 No purposeful active movement, totally dependent, requires full physical care and constant vigilance/supervision										
	1 Assists/Co-operates but burden of task falls on professional/familiar carer										
	2 Can undertake some part of task but needs a high level of support to complete										
	3 Can undertake task function in familiar situation but requires some verbal prompting/physical assistance										
	4 Requires some minor assistance occasionally or extra time to complete a task										
	5 Independent/able to function										
Social Participation	**0** No autonomy, isolated, no social/family role										
	1 Very limited choices, contact mainly with professionals/familiar carers, no social or family role, little control over life										
	2 Some integration, value and autonomy in one setting										
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	4 Occasionally some restriction in autonomy, integration or role										
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Wellbeing	**0** High & constant levels of concern/anger/severe depression or apathy, unable to express or control emotions appropriately										
	1 Moderate concern, becomes concerned easily, requires constant reassurance/support, needs clear/tight limits and structure, loses emotional control easily										
	2 Concern in unfamiliar situations, frequent emotional encouragement and support required										
	3 Controls emotions with assistance, emotionally dependent on some occasions, vulnerable to change in routine, spontaneously uses methods to assist emotional control										
	4 Able to control feelings in most situations, generally well-adjusted/stable (most of the time/ most situations), occasional emotional support/encouragement needed										
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9. DPA Research Network

a. Why have a DPA Research Network?

Whilst there is a lot of research and literature about the behaviours associated with different uninhibited primitive reflexes there is relatively limited research and data looking at the outcome of primitive reflexes inhibition therapies.

The purpose of the DPA Research Network is to collate empirical data in order to research the efficacy of primitive reflex inhibition therapies. At present, the data will be based on your judgements at the start and at the completion of therapy.

b. What is the DPA Research Network?

In brief, the DPA Research Network is asking those members who used primitive reflex-based therapies to use TOMs assessment at least at the start of therapy and at the end of therapy to measure the impact of that therapy. They will be asked to share their case studies with the Research Team who will collate all the submitted data and publish it.

c. How will the Network Work?

- Members will have to have had TOMs training (which the DPA can supply).
- Member's clients should be aware that data is being collected and collated for research purposes, but that all data shared with the DPA and later publicised will ~~me~~ be anonymised.
- Members will receive an annual membership certificate.
- There will be some moderation across the Network to ensure consistency of judgements.
- All Case Studies will be held at the DPA Research Data Bank.
- The Research Team will update members at least annually.
- When sufficient data is gathered, the Research Team will publish their findings to:
    - The DPA;
    - Suitable periodicals, publications, and social media.
    - Appropriate individuals, institutions, and organisations.

10. Help – where to find information and support.

A list of contacts to advise and support, will be placed on the website and updated as required.

Therapy Outcome Measure User Guide and Scales, Pam Enderby and Alexandra John. J&R Press Ltd. ISBN 1 907826 43 6

11. Supplementary Guides and Updates.

Over time it might be useful to circulate supplementary guidance and updates.

Following the publication of this booklet, the following Supplementary Guides will be made available.

1. Assessment
2. Assessment Recording
3. ICD Codes
4. SpLD Behavioural Checklists
5. Activity, Independence and Social Participation Milestones

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