**Appendix 1: Questionnaire**

1. In which country do you work?
2. In which city?
3. What is your organization/affiliation?
4. What is the setting you work in?
   1. Hospital
   2. Private practice
   3. Rehabilitation center
   4. Other\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
5. Do you work in a multidisciplinary team?
   1. Yes
   2. No
6. What is you discipline?
   1. General practitioner
   2. Pediatrician
   3. Child Neurologist
   4. Neurologist
   5. Rehabilitation specialist
   6. Other\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
7. Which other healthcare professionals are involved in your team?
   1. Medical doctor
   2. Nurse
   3. Physiotherapist
   4. Speech therapist
   5. Social worker
   6. Psychologist
   7. Occupational Therapist
   8. Orthopedist
   9. Psychiatrist
   10. Dietician
   11. Other\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
8. How many patients with DMD do you treat each year?
   1. 0-50
   2. 50-100
   3. 100-150
   4. 150-200
   5. > 200
9. How many years of experience do you have in DMD
   1. 0-5
   2. 5-10
   3. > 10
10. What kind of patients do you follow
    1. Children and adolescents
    2. Adults
11. Do you screen actively for behavioral problems in your center?
    1. Yes, systematically
    2. Yes, but not systematically
    3. No, only when parents/patients ask for it
    4. No, never
12. Is there a protocol you follow to screen for behavioral problems?
    1. Yes
    2. No
13. Which person in your multidisciplinary team is responsible for screening for behavioral problems?
    1. Doctor
    2. Psychologist
    3. Psychiatrist
    4. Social worker
    5. Other\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
14. Which tools are used to screen for behavioral problems and when?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Never | Rarely | When indicated | Systematically at fixed ages | Always |
| Questionnaires |  |  |  |  |  |
| Intelligence tests |  |  |  |  |  |
| Neuropsychological tests |  |  |  |  |  |
| History taking |  |  |  |  |  |
| Clinical observations |  |  |  |  |  |
| Semi-structured interview |  |  |  |  |  |

1. If you use specific questionnaires or specific tests, which ones?
2. Which behavioral problems are seen in your patient population and how often?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Never | Rarely | Sometimes | Often | Very often |
| Anxiety |  |  |  |  |  |
| Shyness |  |  |  |  |  |
| Temper tantrums |  |  |  |  |  |
| Yelling |  |  |  |  |  |
| Concentration problems |  |  |  |  |  |
| Learning problems |  |  |  |  |  |
| Social problems |  |  |  |  |  |
| Unappropriated eye contact |  |  |  |  |  |
| Demands a lot of attention |  |  |  |  |  |
| Doesn’t take initiative |  |  |  |  |  |
| Stubborn |  |  |  |  |  |
| Rigid thoughts |  |  |  |  |  |
| Compulsive behaviors |  |  |  |  |  |
| Obsessive thought |  |  |  |  |  |
| Problems with reading |  |  |  |  |  |
| Problems with math |  |  |  |  |  |
| Aggressive behavior |  |  |  |  |  |
| Conduct problems |  |  |  |  |  |
| Sleeping problems |  |  |  |  |  |
| Dependent from adults |  |  |  |  |  |
| Claiming to adults |  |  |  |  |  |
| Worrying |  |  |  |  |  |
| Depressive feelings |  |  |  |  |  |
| Suicidal thoughts |  |  |  |  |  |
| Phobias |  |  |  |  |  |
| Acts too young for his age |  |  |  |  |  |
| Doesn’t finish thing he started |  |  |  |  |  |
| Can’t let go of specific thoughts |  |  |  |  |  |
| Can’t sit still |  |  |  |  |  |
| Day dreaming |  |  |  |  |  |
| Is clumsy |  |  |  |  |  |
| Doesn’t pay attention |  |  |  |  |  |
| Seems absent |  |  |  |  |  |
| Nagging |  |  |  |  |  |
| Not much energy |  |  |  |  |  |
| Rule-breaking behavior |  |  |  |  |  |
| Disobedient |  |  |  |  |  |
| Eating disorders |  |  |  |  |  |
| Can’t be alone |  |  |  |  |  |
| Doesn’t have friends |  |  |  |  |  |
| Can’t see things from the point of view of others |  |  |  |  |  |
| Asking too many questions |  |  |  |  |  |
| Prefers to be alone |  |  |  |  |  |
| Can’t express emotions |  |  |  |  |  |
| Strange behaviors |  |  |  |  |  |

1. Which types of intervention do you use and how often?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Never | Rarely | Sometimes | Often | Very often |
| Referral for psychodiagnostics process |  |  |  |  |  |
| Behavioral therapeutic approach |  |  |  |  |  |
| Parental counseling |  |  |  |  |  |
| Psychopharmaceutical treatment |  |  |  |  |  |
| Client centered therapeutic approach |  |  |  |  |  |
| Contact with other healthcare professionals |  |  |  |  |  |
| Referral for psychotherapy |  |  |  |  |  |
| Contextual/systemic therapeutical approach |  |  |  |  |  |
| Referral for psychiatrist |  |  |  |  |  |
| Neuropsychological examination |  |  |  |  |  |
| Psychoanalytical therapeutical approach |  |  |  |  |  |
| Referral for psychosocial support |  |  |  |  |  |

1. How do you agree with the next statements?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | I strongly disagree | I  disagree | Neutral | I agree | I strongly agree |
| There should be more attention for behavioral problems in boys with DMD in our center. |  |  |  |  |  |
| I have enough knowledge about behavioral and neurocognitive issues in DMD. |  |  |  |  |  |
| There should be a psychologist or behavioral specialist in a team that treats boys with DMD. |  |  |  |  |  |
| It is difficult to find proper help for the behavioral aspects of DMD. |  |  |  |  |  |
| Parents are not enough aware of the behavioral difficulties that can be caused by DMD. |  |  |  |  |  |
| Psychopharmaceutical drugs should not be used in boys with DMD. |  |  |  |  |  |
| The behavioral aspects of DMD are underestimated. |  |  |  |  |  |
| There should be more attention for behavioral problems on international congresses like WMS, ICNMD, ... |  |  |  |  |  |
| Behavioral problems or neurocognitive symptoms are not the focus for clinical care. |  |  |  |  |  |
| When parents receive the news about the diagnose of DMD, eventual behavioral or neurocognitive aspects should be mentioned. |  |  |  |  |  |
| There is not enough time to screen for behavioral or neurocognitive aspects of DMD. |  |  |  |  |  |
| There should be a manual to help clinical experts screen for behavioral problems. |  |  |  |  |  |

1. If you or your center are willing to participate in further research about behavioral and neurocognitive aspects of DMD or in international collaboration for clinical care, please leave your email address.
2. Are there issues about behavior or neurocognition in DMD you missed in this survey? Please, feel free to give any comments or considerations.